

CITRUS CLOUDS ON PLANET GOOFY: THE
REPORTED EXPERIENCES OF CHILDREN WITH
LEARNING DISABILITY

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Doctoral degree in Education

by

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First and foremost, thank you Jesus.

Although there is only one name on this thesis, there are many who deserve credit for their part in this process. There is a danger in singling out individuals, especially as this has been a long journey and there have been many who made it a little less stressful. I do however wish to acknowledge:

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*This is dedicated to the learners who shared their stories with me, and the
countless others who remain unvoiced.*

ABSTRACT

The purpose of this study is to illuminate the lived experiences of children with specific learning disability in an attempt to move beyond the deficit and reductionist models of theorizing learning disabilities that currently inform our understanding. A paradigm shift is proposed, a shift in focus towards a holistic or comprehensive view of the person with learning disability. By viewing the phenomenon from the inside, as it were, I shift my focus from “what it is” to “how it is experienced” (Hall, 1998). It is suggested that a change in focus from the deficit to the whole child in his context will better inform practice

This research follows the empirical phenomenological tradition, a qualitative analysis of everyday accounts of living with LD. Justification is given for using life history methodology in order to garner insights into the experiences of a child with learning disability. Five informants between the ages of 12 and 14 years were selected to participate in this study. A multi-method approach to data collection was used. Data were collected from a number of sources, including audio journals kept by participants, guided conversations typical of life history research and visual representations such as collages or life maps submitted by the participants. Data, interpreted on multiple levels, are represented in narrative form.

Findings challenge current thinking around inclusive education by suggesting that learners with LD experience exclusion in a system meant to create a sense of inclusion. It is in the mainstream that the “identity as LD” is constructed because of the comparison to the performance of peers who do not have LD. However in a specialised educational environment where peers all presented with the same learning differences, difficulties and styles, instead of comparison there is a sameness. I suggest that this leads to the development of an “identity as capable.”

Finally there is much we can learn about pedagogical intervention or management from these informants’ experience of LD.

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LIST OF ABBREVIATIONS

DOE: Department of Education, unless otherwise stated this refers specifically to the South African National Department of Education

DSM IV: Diagnostic and statistical manual of the American Psychological Association 4th edition

IE: Inclusive education

LD: Learning disability

LLD: Language learning disability

NJCLD: National Joint Committee on Learning Disabilities

NVLD: Nonverbal learning disability

PART ONE: The Process

*being the
procedure,
course,
development,
route,
method
manner,
means*

...in which I set up the camera, focus the lens and push the button

CHAPTER ONE

INTRODUCTION AND RATIONALE: Setting up the camera

Pretty much everyone has both learning abilities and learning disabilities (Sternberg & Grigorenko, 2000:10)

1. Introduction:

The **purpose** of this study is to illuminate the lived experiences of children with learning disability in an attempt to move beyond the deficit and reductionist models of theorizing learning disabilities that currently inform our understanding of these children. An approach such as a biographical and interpretive approach that considers the experience of learning disability, could lead to a broader understanding of learning disability. This alternative understanding may suggest new ways of conceptualising learning disability.

For many educators there is a realization of the increasing number of children failing to cope academically, an increase in the number of children being labeled “learning disabled” (LD). It is obvious even from a cursory reading of the literature in the area of learning disability that debates abound. A clear sense of what LD is, who “has it” and how it can best be understood fails to emerge even when one moves beyond such a cursory reading. With the growing number of children being diagnosed “learning disabled,” many of whom are being educated in a second language, the urgency to fully understand these children is obvious. The *Education White Paper 6* (Department of Education, 2001)¹ advocates early identification of children with “barriers to learning,” such as those with learning disability, in order to offer appropriate support. That support would include flexible curricula and assessment strategies, a review of age grade norms, and a re-shaping of the special

¹ Department of Education hereinafter referenced as DOE

education sector. Included in this re-shaping is the development of special schools as resource centres and creating full service schools (DOE, 2001).

There is no separate focus on any one specific category of learner in *Education White Paper 6* (DOE, 2001), with reference being made broadly to “learners with barriers to learning.” This includes both intrinsic barriers, referred to as “physical, mental, sensory, neurological and developmental impairments, psychosocial disturbances, differences in intellectual ability” and extrinsic factors such as life experiences and socio-economic deprivation (DOE, 2001:17). The learner with LD, regardless of how one defines it, would fall into the group of “learners with barriers to learning.” Who then is this learner?

The controversies around what LD is and is not are discussed in detail in Chapter Two. However the two words “intrinsic” and “extrinsic” occur in most debates around LD – just how much weight is given to each varies across definitions. The intrinsic view implies that those with LD have a fault or malfunction in specific areas of the brain, in other words the problem lies within the individual. Frank’s (2002:10) description of LD as a problem with a *neurological basis*, Hirshelwood’s finding that dyslexia has as its cause the *activity of the angular gyrus* (Thomson, 1990:4), and Shaywitz’s finding of *greater activity in Broca’s area* (cited in Frank, 2002:13), all suggest an intrinsic physiological or biological basis. The proponents of the extrinsic view claim that LD is not in fact a problem within the individual at all, but place the blame for the child’s failure to learn squarely on the educational or learning context, or even the school or education system. Both Hartman (1999) and Levine (2002) suggest that a group of children present with learning difficulties in the classroom because the system does not teach them the way they need to learn. Therefore the problem is one of the *selected education method*.

Although there is an enormous body of research into the area of learning disability² and language learning disability in particular, I am convinced that there is a gap in our understanding of this phenomenon. We need to acknowledge that there are multiple “understandings” of learning disability (Brechtin, 1999) which must be explored if we are to adequately serve this growing population of learners. That there are multiple ways of knowing (Eisner, 1990, Guba, 1990, Phillips, 1990) is more widely accepted in the social and human sciences than in the medical and health sciences, the fields where much of the research into LD is generated.

I believe we need to seek new ways of understanding LD as the lens we currently use to research learning disability is resulting in tunnel vision. The dominant paradigms result in research that only throws light on very specific aspects of the problem. Too much still lies in the shadows, on the periphery. I believe an alternative approach to research in this area is warranted. This alternative approach is recognizably holistic and seeks primarily to understand the story behind what teachers, educational psychologists and medical practitioners regard as a barrier to learning or a learning disability. The biographical interpretive approach that is mooted may shift the focus from attempts to find and understand the *deficits* “suffered” by an individual with learning disability, to attempts to understand their *needs* and how they see and *define themselves*. This study therefore concerns itself with how children with LD perceive and define themselves and how this process of self representation, which takes the form of narrative or story, provides a fresh perspective for looking at LD. Narrative knowing, according to Polkinghorne, bridges the divide between research and practice (1988). Thus a narrative approach may not only result in a fuller or holistic understanding of learning disability, but certainly should result in what Kathard (2006) refers to as “reframing goals” for therapy/ intervention. The reasoning behind this view and thus the rationale for this study is discussed below.

² For the definition used in this research see pp 25-27.

2. Rationale

The rationale for this research developed initially from a personal experience of LD, but it was only when I began a career in academia that I allowed the “personal troublings” to develop into potential research questions. Therefore in presenting the rationale it is necessary to first give the personal rationale. I follow this with a discussion on what I believe to be the theoretical gaps as “theoretical rationale,” and attempt to show how these gaps arise because of the dominant methodological approaches in the field, described under the subheading “the methodological rationale.” By presenting the rationale this way I hope to show how my thinking in different aspects of my life converged to the point where I felt I had reason to pursue this research.

2.1. The personal rationale

Before detailing the rationale for this study I provide a brief autobiographical sketch to position myself (Chanfrault-Duchet, 2004). This is necessary not only in view of Denzin and Lincoln’s (2003:9) description of a researcher, who they describe as an “interpretive bricoleur,” as someone who: “understands that research is an interactive process shaped by ...[her] personal history, biography, gender, social class, race, and ethnicity, and by those of the people in the setting.” It is also relevant to the rationale, as my interest in this area of research is indeed both personal and academic. I come to this research as a speech–language therapist with a special interest in the child with LD, an interest which developed initially through my work experience in remedial school environments and my private practice case load. It was an interest that was to become a passion when my own child experienced specific scholastic difficulties. While observing my clients and then my own child I came to see a world that was not lacking, not ‘in deficit,’ but rather one that was in many ways richer than my own, one where thinking was more often than not ‘outside the box.’ I also became increasingly aware that the way these children saw

themselves was directly related to comments made by others, including parents, teachers and friends. I began to question how much of an impact their experiences had on their identity construction, particularly their identities as ‘learners with learning difficulties.’ I also began to question whether they should even be so described, in other words if there was a problem that needed identifying, a label, and management, was that problem even within the child? I recently became a clinical tutor, training student speech–language therapists in a language learning disability clinic. At this point there was a conflict between what I felt in my gut about the children we were seeing and what the literature was telling me to teach my students. The theory I was teaching was informed by a literature that suggested children with LD were “broken” and needed “fixing.” As a speech-language therapist my role, and therefore what I was teaching my students about their own roles, was to explore and then “close the gaps” in areas such as phonological awareness, auditory processing and language processing. Whilst I accept that there are areas where intervention may be necessary, I did not find literature that really told me about these children as individuals, how they defined themselves, who they were, other than that they suffered many “deficits.” It is this conflict that has motivated the present research. As a speech-language therapist who has worked with children with learning disability for over 20 years, I have come to an understanding of these children that does not resonate with what I read in the literature that informs practitioners in this field. I agree with Kathard (2001), who argues that: “...a clinically situated profession [such as speech-language pathology] is in dire need of theory about subjective dimensions that can be appropriated into practice.” Kathard (2001) goes on to criticize research which falls short of producing the kind of knowledge that would be truly beneficial to the profession, which is “knowledge for practice.” I believe that the current research in the field is reductionistic (Archer & Green, 1996), a discussion I take up below, and is therefore not useful in informing our practice.

One area in particular caused a shift in my thinking. Despite the wealth of information available about learning disabilities, none of it allows access to the subjective, inner world of the child with learning disability to reveal what I believe to be an enviable richness. The following illustrates this point. Malapropisms are common in children with learning disability due to their poor auditory perceptual skills (Vallance & Wintre, 1997). Children who mispronounce words or produce malapropisms are often ridiculed and certainly always corrected as these are seen as ‘deficits’ or ‘problems.’ As a clinician trained to remediate language disorder I would hear parents and teachers frequently comment on the malapropisms so typical of these children. Yet more often than not these malapropisms resulted in not only humorous but also quite sensible utterances. Thus what may be seen through one lens as a deficit, “poor vocabulary,” may be seen through another lens as a fragment, “word-finding difficulty,” of a larger whole, “learning disability.” Yet this could also be seen or reinterpreted from the child’s point of view. This is exemplified in the title of this report, which comes from a wealth of malapropisms uttered by a child with learning disability. Who wouldn’t rather live in a world where cirrus clouds were ‘citrus’ and where all planets, not just Pluto, were named after Disney dogs?

So to clarify the “fundamental assumptions, experiences and passions behind [my] inquiries” (Cole & Knowles, 2001:48), I believe the lens we currently use to research learning disability is resulting in a limited understanding, as depicted in Figure 2 below. Too much still lies outside our field of vision. Research which assumes various “truths” may be responsible for perpetuating an incorrect understanding or a *mis*understanding of the phenomenon of LD. In other words research that is rooted in positivism or logical empiricism, where only one “truth” is recognized, may only be revealing one part or aspect of the story. This point is discussed further below, as the theoretical rationale for this research, which provides the analytical framework.

2.2. The theoretical rationale

There are two conceptual paradigms which currently predominate in the research, neither of which, I believe, leads to satisfactory theorizing of learning disability. Lewis (1998:94) describes four theoretical models of LD, each one dominating for a decade between 1950 and 1990: the Medical, Psychological Process, Behavioural and the Cognitive or Learning Strategies Models. All four models have their roots in the **reductionist** paradigm, as each attempts to “segment learning into parts” (Lewis, 1998:94), as well as the **deficit** or pathology paradigm as each of these four models “proposes a diagnosis, the goal of which is to document specific deficits” and “instruction in each model is deficit driven” (Lewis, 1998:94). At a broader paradigmatic level all these models are underpinned by logical empiricism.

The body of research that informs us about learning disability is still largely framed within the medical or deficit paradigm, particularly research from the Health Sciences. The **deficit model** can best be described as inextricably linked to the medical model, which has implicit in the term ‘disability’ a connotation of deficiency. Oliver (1996:37) suggests that:

...the medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image: physiotherapy, occupational therapy, speech therapy, clinical psychology; each one geared to the same aim- *the restoration of normality*. ...each of these pseudo-professions develops its own knowledge base and set of skills to facilitate this. They organize their interventions and intrusions into disabled people’s lives on the basis of *discreet and limited knowledge and skills*. (emphasis mine)

Research that comes from what Oliver regards as “pseudo-professions” then is likely to be reflective of these roots in the medical model. The medical model, with its focus on “pathology” or deficit, “emphasizes the [child’s] liabilities and short-comings,” (Pijl & Van den Bos, 1998, quoting Myers and Hammill),

and is exemplified by research that suggests etiological factors such as faulty neurological circuits and hemispheric dominance. Ratner and Harris (1994) devote 6 pages or some 2000 words to describing the *deficits* noted in a child with LD. These include reading, spelling, phonological awareness, written language, oral language, auditory and visual perceptual skills. The focus within this paradigm is on what is *wrong*, what is *missing*, what the individual *can't* do, how and why he *fails*. Gillman (1999) describes research in the field as being “problem-saturated.” The deficit focus perpetuates the myth that the pathology lies within the child (de Pear, 1995), foregrounding the failure of the child to cope in the system rather than examining the failure of the system to cope with the needs of the child (Booth, 1998:83). Research in this paradigm pays scant attention to the child's assets or strengths, nor does it explore whether the child feels “in deficit” or “less than” his peers. It does not look at the condition from the learner's point of view. This is where I propose a significant shift or re-directing of the research gaze from a focus on the pathology or deficit to a focus on the human. The pertinent question then becomes: what can we learn about children with LD if we look at the problem from their point of view? I return to this question in Chapter Three. However at this point I present a collage offered by one of the informants in this research to show how she understands her LD. Note how little attention she gives to the *deficits* and in fact how many positive words she uses.



Figure 1: Collage submitted by informant H. to show her experience of LD

A deficit focus implies children with LD cannot learn. Management from every discipline is framed around how to make them learn. Within the deficit model or paradigm, management involves the “fixing” of what educators identify as specific deficits or problems (Ainscow, 1998:11), or “filling in the gap” in terms of skills and not on anything else. The focus is on improving the basic skills to close the gap between achievement and “general ability” or “potential” (Westby, 2000:4), regardless of the controversy around establishing this potential.³

Furthermore, the deficit focus ignores the experiences of a child with learning disability to a large extent. Kathard’s (2001) critique of the pathology focus of research informs my own. Although her work is in the field of stuttering, those “human dimensions” Kathard refers to as being part of the stuttering experience, such as “hurt, pain, grief, hope and courage,” and which are ignored in current research, are, in my view as both a parent and a clinician, similar to the experiences of a child with learning disability.

I describe the other predominant paradigm as **reductionist**. I use this term to suggest that such research is conceptualised from the view that LD can best be understood by reducing it to fragments. The phenomenon of LD is divided into separate units, each of which is researched. Pijl and Van den Bos (1998), and Lewis (1998), are critical of research in the field to date for being compartmentalized and ‘reductionist.’ Each study focuses on one small aspect of the child, for example language disorder, reading or spelling difficulty.

Furthermore, much of the research to date has been discipline specific, as well as microscopic. When speech-language therapists look at LD, they look at very specific parameters: phonological awareness (Most et al., 2000), nonword repetition as a predictor of reading readiness (Metsala, 1999), the impact of poor auditory discrimination on spelling ability (Joly-Pottuz et al., 2008). In

³ This is discussed in Chapter Two.

other words they continue to research discrete, often unconnected, units. To use a photographic analogy, this focus on specifics provides only a narrow depth of field, with a limited area in focus. The child is then defined by the rules that are generated as a result of such research.

However this is based on a faulty premise – that in order to understand the whole we need to know the parts, and synthesize these parts to form the whole. I do not believe this microscopic or reductionist focus informs our understanding. It may lead to an overproduction of knowledge – smaller and smaller areas of specialization (Booth, 1998). I am concerned that we may, like the six blind men in the folktale, all be touching part of the elephant and seeing different things.⁴ Though each may be partly in the right, all are wrong!

Lewis debunks as a myth the belief that it is “possible to understand a phenomenon merely by understanding the various parts in detail and then aggregating these discrete parcels of knowledge” (Lewis, 1998:99). Reason and Rowan (1981:xiv) suggest this reductionism results in “studying variables rather than persons“ and as “a flight from understanding in depth.” Oliver (1996:139-140) also criticizes research that fragments and quotes Rowan: “...treating people as fragments... is usually done by putting a person into the role of ‘research subject’ and only *then permitting a very restricted range of behaviour to be counted* (emphasis mine). It is therefore not surprising that the knowledge base that is developed from such research may seem to be lacking.

Managing LD within this paradigm means focusing on one area or fragment at a time, such as focusing on letter-sound identification, phonological awareness, visual sequential memory. We provide the child with support in these discrete

⁴ Six blind men each reach out and touch an elephant. The first feels the elephant’s broad side and concludes an elephant is like a wall; the second feels a sharp tusk and concludes it is like a spear; the third man touches the trunk – long, flexible and writhing and concludes that an elephant is like a snake; the fourth man reaches out and touches a thick, strong, sturdy leg and concludes an elephant is like a tree; the fifth concludes the flat, flapping ear is like a fan and the sixth, who touches the rough tail thinks an elephant is like a rope.
http://www.geocities.com/sunitra_in/blindmen.html

areas and wait for a significant improvement in his ability to read. Therapy, especially speech–language and occupational therapy, is geared to providing direct support for, and encouraging development of those skills that appear weak. Yet in doing this we are perpetuating the child’s difficulties as Dudley-Marling says:

Since learners can make sense only by relating what is being taught to prior knowledge, the practice of fragmenting learning into isolated skills makes it impossible for the learner to make sense (Dudley-Marling, 1993:94).

The time is right to acknowledge that this approach to the study of LD is no longer tenable. I believe an alternative approach to research in this area is warranted. It is my view that by attempting to understand how the child with LD actually experiences his/her condition we may then move beyond the deficit and reductionist understanding currently dominating research discourse. In other words I believe that by attempting to explore the experiences of the child with LD, we may gain an understanding of the *whole* phenomenon, its impact on the learner’s day to day functioning and ultimately his identity. It may then be possible to use this understanding of the child’s experience of LD to guide our intervention. By asking questions about how the experience of LD impacts on both the learner’s interpretation of his/her condition and his/her identity, educators may see different areas for intervention as priorities. Instead of focusing on fixing the deficits we may be able to look at changing experiences. Using a methodological approach that allows for such an exploration is the first step. In what follows in this chapter I will expand on this argument and attempt to justify the research on which this report is based.

2.3. The methodological rationale

Equally significant for the rationale of this study are the methodological approaches employed by researchers in this field. A review of methodological

approaches reveals that the favoured methodologies perpetuate the reductionist, deficit focus. In Chapter Two I discuss this in more detail; however in appendix 1 I provide examples by listing some of the titles of articles published in recent volumes of the *Journal of Learning Disabilities*, one of the definitive journals in the field. The focus on the “deficit” as well as the tendency to fragment or reduce LD to ever smaller components is apparent even in the titles of these articles (refer page 250).

Furthermore research that purports to take the child’s view into consideration does not really do this. It is apparent from a review of the literature that not only does much of the existing body of research in the field of LD ignore the child’s assets or strengths, but a holistic view of the child is also not taken. By this I mean a view that acknowledges that the whole is greater than the sum of the parts. In other words, for my purposes it means that we cannot begin to understand learning disability merely by trying to break it down into specific aspects or components and understand each of those in turn. By ignoring how the *learner* understands his condition we may well be missing cues to more effective intervention.

It is the central argument of this study that we need to research the perspective of the child with learning disability within a different framework in order to develop different “understandings” of learning disability (Breachin, 1999). I believe the only way to address the gaps and silences in the literature is to use an alternative methodology which revolves around the child’s self-conception and self-presentation. I propose a paradigm shift, from both the deficit-focused and reductionist (Bailey, 1998) frames which predominate in the research to a model that requires a recognition that the whole is greater than the sum of the parts (Lewis, 1998), with a particular focus on the influence of context (Cole & Knowles, 2001) and what could be termed ‘self-analysis.’ Essentially, the context includes the ways in which children with LD interpret their condition. Reason and Rowan (1981:xiv) go as far as to suggest a researcher should *not*

research people without taking into account their social contexts, in other words “all that gives their actions meaning.” Therefore in order to inform our understanding we need to look instead at whole lives, at lived experiences, and their concomitant interpretations by children with LD. In other words, we need to focus on the different ways in which young learners with LD understand or interpret their condition. The life history methodology is particularly pertinent in a study of this nature.

Hall (1998) supports this move away from research that is “scientific”- a clear reference to the positivist or empiricist approach:

I agree with Benner when she writes that the scientific study of education is “antiquated at best.” Scientific study is not going to produce positive change. I feel that changes in education will come when we listen to the stories of persons who have been treated as deviant and to the voices of the children and their families that have been too long ignored (Hall, 1998:5-6).

A paradigm shift may allow for “reinterpreting the LD experience in a more productive and positive manner” (Gerber et al., 1996:98). This alternative understanding may suggest new ways of conceptualizing learning disability. This broader view which takes into account contextual factors as well as the ‘voice’ of children with LD may, by encouraging reflection, lead to changes in the way we teach or manage children with LD. It is the deficits rather than the strengths which currently receive attention in the education system (Bauer, 1993:3). Identification of the child’s strengths would result in the planning of appropriate management strategies to allow for the experience of success rather than failure.

I do not believe we can best serve this growing group of children without fully understanding them beyond the deficits they may display. The focus needs to shift to how they **do** learn and to recognize the difference rather than the

deficit. Jones (1993:61) has supported the view that learners with special educational needs possess differences, not deficits:

If the curriculum is to empower challenging students professionals must provide opportunities for students to exhibit their strengths in social contexts through the roles of learner, teacher, collaborator, and must recognize students with special needs as possessing differences, not deficits (Jones, 1993:61).

To conclude then, I believe the lens we currently use to research LD has a narrow depth of field with only a limited component of the big picture in focus. It is a focus which only throws light on very specific aspects of the problem, resulting in confusion. Too much still lies in the shadows, on the periphery. We need to shift our focus in research as depicted in the diagram below in order to deconstruct the label 'learning disability.' In other words it is time to step back and see the wood instead of just the trees. Then I believe we may start to move towards an understanding of LD that ultimately leads to consensus on redefinition, recognition and remediation.

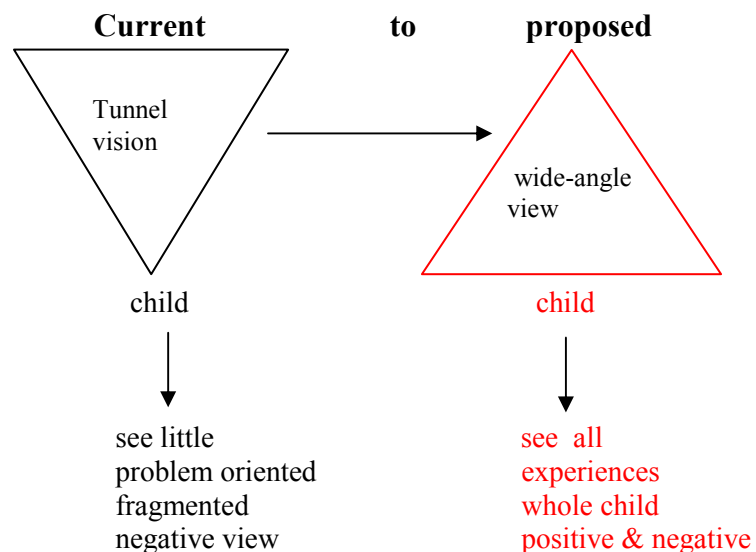


Figure 2: Diagram showing the shift in focus: red depicts proposed research

I believe the answers to the following questions will help to provide just that – an alternative understanding of LD, one that reflects a broader view and therefore one that throws light on LD from the insider’s view or perspective. Illuminating what it is like to “have” or experience LD may also lead to new developments in management, particularly educational management and remedial interventions.

3. Critical questions:

1. What are the lived experiences of children with learning disability?
2. How do children with LD interpret their condition?
3. What insights can the life-history approach provide into the nature of LD and how can this facilitate pedagogical interventions?

4. Scope of the study

In order to answer these questions this research followed the “empirical phenomenological tradition” described by Bargdill (2000:193) as a “qualitative analysis of people’s everyday accounts of the phenomenon being studied.” The phenomenon in this case was LD. I used a life history methodology as this allows for the informants to (re)construct their *own life* stories, foregrounding what they believe or want to be important. It was hoped that this would allow for insights into the experiences of a child with learning disability that are not being identified through the existing research to emerge.

Six **participants or informants**⁵ (Cole & Knowles, 2001, Kazmierska, 2004) between the ages of 12 and 14 years, were selected to participate in this study. One of these was my own child. Older children were selected as Badian

⁵ The use of the word “informants” to describe the participants in this research is selected deliberately and follows Cole and Knowles (2001) and Kazmierska (2004). It implies that the power lies with the “researched”- in this case the child, the holder of the information, who is not merely participating in the researcher’s agenda. Goodson and Sykes (2001) endorse the use of the word “informant” as it does not “Other” the participant.

(1996) states that a definitive diagnosis of dyslexia (the term she uses), can only be made after the age of 10. Furthermore due to the nature of the study and the need for the informants to articulate their experiences (Bargdill, 2000), younger children were not included.

Research sites were selected based on access to the target sample population. One site was a remedial school and another was a private, mainstream school. Admission criteria to the remedial site stipulated a diagnosis of LD⁶ as the primary reason for scholastic failure; the mainstream site had a remedial unit which provided support for learners who had a positive diagnosis of LD and who had either had a period of placement in a remedial school, or required ongoing support in the mainstream school. Additional factors motivating the final selection of these two sites was my existing relationship with the management and pupils at the schools, as well as proximity (convenience) to allow for easy and regular contact with informants.

5. Theoretical and analytical framework

It is incumbent on me as the researcher to state up front how I understand “the truth” and how this view provided the framework for the research (Connor, 1999, Hirschman, 1979). As a speech-language therapist whose initial undergraduate study was completed nearly 30 years ago, my early research training was cemented in positivism: the notion that good science finds the **one real truth**, normally by examining a cause and effect relationship between variables. However I have never felt comfortable with this. I applaud the growing legitimacy and recognition of alternative interpretive paradigms, even in health sciences which have traditionally been the domain of positivism, which is due to:

⁶ The difficulty in making this diagnosis and the merits or otherwise of using standardized assessment procedures such as IQ tests has been thoroughly explored in the second chapter of this research report.

...the decreasing relevance of the positivist ideology selectively coloured by the growing confidence of social science researchers in the capability of qualitative research to adequately respond to the needs of observing, interpreting and analyzing educational and social development data (Abdi, 2001).

Ontologically I believe, like Tinelli (2000) that “there are multiple realities,” and epistemologically knowledge is produced and shaped by those in an interactive exchange. In other words, I believe in the subjective, constructed nature of reality (Denzin & Lincoln, 2003, Donnell, 1999). It is primarily for this reason that I have chosen phenomenology as a guiding meta-theoretical framework for my study. As Babbie and Mouton (2006) rightly point out:

The phenomenologist emphasizes that all human beings are engaged in the process of making sense of their (life) worlds. We continuously interpret, create, and give meaning to, define, justify and rationalize our actions. According to the phenomenological position, the fact that people are continuously constructing, developing and changing the everyday (common-sense) interpretations of their worlds(s), should be taken into account in any conception of social science research (Babbie & Mouton, 2006:28).

I have situated my research within the interpretivist paradigm as I aim, through this research, to develop a fuller understanding of learning disability. The interpretivist paradigm allows for people to tell their stories, affording a researcher the opportunity to gain insight into the perspectives of the “story tellers” or research participants; the objective of research within this paradigm is *understanding* (Hall, 1998). As I aim, through this research, to develop a fuller understanding of learning disability by viewing the phenomenon from the inside, as it were, I shift my focus from “what it is” to “how it is experienced” (Hall, 1998). I am researching the views of children with LD – the views they have of their own (subjective/ perceived) reality (Donnell, 1999) and therefore the interpretivist approach with its relativist ontological premise (Denzin & Lincoln, 2003) is appropriate.

Furthermore, as mentioned above, I am attempting to move away from the reductionistic view that is perpetuated by much current research in the field, particularly that which is emerging from the health sciences. This is in order to understand holistically, in a manner that allows for the inclusion of the variables that add to the participants' reality, rather than "isolating" these variables as in reductionistic approaches (Bolton, 2001:363). There is support for this in Laing's view that one cannot understand a patient's "existential position" by viewing him merely as a bundle of symptoms (Jenner, 2001). It is my argument that this is what current research tries to do. I deal with this in detail in Chapter Two.

I believe, like Henning (2004:20) that: "knowledge is constructed not only by observable phenomena, but also by descriptions of people's intentions, beliefs, values and reasons, meaning-making and self-understanding." According to Churchill (2000:45) when it is important to know the meaning of experience as lived, what is needed is the *report* of the experience; it is not necessary to look for the *mechanism* of the experience. Therefore in order to understand how children experience their learning disability, how they make sense of their experiences, I ask them to tell their own stories. It is in telling their stories that I believe these children show how they make sense of their world (Hall, 1998), as well as reflect their identities (McMillan, 2003). In addition to this, labels such as "learning disability" can be described as *objective* knowledge, or according to Giddens (Thursby, n.d.), as structure. I wish to explore the *subjective*, the experience of LD. I wish to illuminate the agents' reality. I therefore attempt to shed light on how, or even whether, children with LD reproduce structure; in other words behave in a way that is defined by conventions, prior knowledge and expectations.

As mentioned earlier, the meta-theoretical paradigm or philosophy that best suits my purposes is phenomenology, particularly social phenomenology, described by Laing (1967) as "the science of my own and of other's

experience,” and hermeneutic phenomenology. Giorgi (2002:9-10) describes phenomenology as a “philosophy of intuition” where “fidelity to the phenomenon” is what is important. Phenomenology looks at lived experiences, and goes as far as to debate whether reductionism is even possible. From my critique of the reductionistic nature of current research in the field of learning disability, it should be apparent why phenomenology appeals to me.

My motivation for this research is a deeply personal interest in the topic, and thus hermeneutic phenomenology seems to provide the most appropriate “frame” within which to position myself. Ricoeur describes the nature of the link between hermeneutics and phenomenology by suggesting that “each presupposes the other.”⁷ Hermeneutic phenomenology is both descriptive and interpretive (Connor, 1999). In other words it allows for an exploration of what a specific experience is like for a specific group of people and “seeks to make meaning out of life-world experiences” (Connor, 1999:14).

Narratives, or “the stories people tell about themselves...reflect identity [and] what they believe about themselves and others” (McMillan, 2003, citing McLaren). Polkinghorne (1988:11) justifies narrative as the only way to understand human experience and behaviour:

Narrative meaning functions to give form to the understanding of a purpose to life and to join everyday actions and events into episodic units. It provides a framework for understanding the past events of one’s life and for planning future actions. It is the primary scheme by means of which human existence is rendered meaningful. Thus the study of human beings by the human sciences needs to focus on the realm of meaning in general, and on narrative meaning in particular.

Rodriguez (2002) tells us that compelling narratives encourage us to change the world and results in “interpretations that make new meanings, experiences,

⁷ (www.ai.mit.edu/people/jcma/papers/1986-ai-memo-871/section3_6.html).

understanding of the world.” Therefore this is an appropriate framing for such a study as I am attempting to understand the world of the child with LD.

6. Methodology

It is clear that we need to research the perspective of the child with learning disability within a different framework in order to develop different understandings of learning disability (Badian, 1996, Brechin, 1999), understandings that recognise that the whole is greater than the sum of the parts (Lewis, 1998). The theory that exists is inadequate for understanding the individual’s experiences (Allan et al., 1998:21). What is needed is a comprehensive, holistic view of learning disability, a focus that can only develop by looking at life experiences. One way to do this is by researching lives in context, in other words examining the lived experiences of children with LD, as:

...the life history technique documents the inner experiences of individuals, how they interpret, understand and define the world around them...it comes to lay bare ...their assumptions and what it is they find problematic about...their lives in particular (Faraday & Plummer, 1979:776).

The value of using life histories in research in social and human sciences is well documented (Atkinson, 1999, Cole & Knowles, 2001, Josselson & Lieblich, 1993, Kathard, 2003, Plummer, 2001), and allows for the crossing of discipline boundaries so lacking in research in the field of LD. Using a life history methodology allows for insights into the experiences of a child with learning disability that are not being identified through the existing research. A life history methodology allows for a move away from rigid empiricism, positivism, reductionism and the deficit-based views perpetuated by existing research. This is expressed by Drewey and Winslade as a denunciation of:

..traditional Western views which *focus on personal deficits in ways that speak of failure* rather than accomplishments, that produce social hierarchies (*experts who are presumed to know more about peoples' lives than they know themselves*)(emphasis mine) (Drewey and Winslade, 1997 in Salter, 1998:12)

According to Cole and Knowles (2001) one of the purposes of life history research is to improve or expand our understanding of a particular condition or phenomenon and: “draws on the individual’s experiences to make broader contextual meaning” (Cole & Knowles, 2001:20). Current research that purports to give the perspective of the learner is critiqued in the following chapter. There is an acknowledged need for research into the perspective of the learner or child with learning difficulties (Atkinson, 1999, Lloyd-Smith & Davis, 1995). Therefore in searching for a different reality, a new way of understanding learning disability, I have elected to illuminate lived experiences as: “lived experience,...as thought and desire, as word and image, *is the primary reality*” (emphasis mine)(Bruner, 1986:5). Thus the result is not only a holistic view but also allows for the voices of those with learning disability to be heard (Gillman, 1999:238, Webb, 1999:48). It allows for the informants to (re)construct their *own life* stories, foregrounding what they believe or want to be important. It is hoped that through this a “clear and unobscured sense” (Kavale & Forness, 2000:240) of learning disability may begin to emerge.

As the data are being collected in order to understand the lived experiences or the everyday experiences of a child with learning disability, a qualitative methodology is the preferred methodology. Quantitative methods, according to Chappell (1999:103), fail to develop our understanding of the everyday world. This study focuses on human behaviour which can only be fully understood by taking into account context, meanings and purposes (Guba & Lincoln, 1998). Qualitative research which “uses methods of data collection which are flexible and sensitive to the social context of the research” (Mason, 1996, in Chappell, 1999:103) is therefore the selected orientation. Furthermore, a qualitative methodology allows for the subjectivity of both the researcher and the

participant (Chappell, 1999:103). I position myself firmly with McKenzie (1997) who suggests objectivity is “an illusion,” and with Mehra (2002) who suggests a biased researcher is an honest researcher, and I acknowledge the subjective nature of this research. Mehra (2002) goes further when she describes the subjectivity inherent in research by stating: “who I am determines ...what I want to study.” My own prior understanding of LD is something I am aware of and cannot exclude as further influencing the subjective nature of this research (Turner, 2003). I come to the researcher’s role with a personal involvement with children with LD who I do not see fully described in current research. My personal experience of LD in my own family will no doubt have an impact on where I situate myself as an interviewer/ researcher, so I have declared my “baggage,” that is the preconceived ideas that I bring to this process (Meier, 1998). In addition to this there are pragmatic reasons for selecting this specific qualitative methodological orientation, the life history. Goodson and Sykes (2001:20) suggest:

...as a general rule life history research is more likely to appeal to the incurably curious who are interested in, and fascinated by, the minutiae of others’ lives, and particularly how people make sense of their experiences and of the world around them.

This describes the “comfortable fit” between me as the researcher and the selected research methodology. Lest this is seen as flippant, I do firmly believe using a life history methodology is the best way of answering the research questions and achieving the purpose of this research. It is apparent that a life history methodology will allow for the holistic or panoramic view of learning disability proposed above. To paraphrase Faraday and Plummer (1979:777):

Through the use of the life history method, the [child with learning disability] is seen as much more than [disabled]. As we follow [children with learning disability] over their different life experiences, we see generally that [learning disability] constitutes only a small fragment of any one individual’s life.

7. Definition of terms

Learning Disability:

The issue of definition is fundamental to our understanding of these children. This is, I believe, where much of the controversy in the literature is “birthed.” I will discuss the evolving definitions that abound in the literature in the following chapter where the complexities inherent in attempting to define what LD is and who ‘has it’ will become apparent. It is necessary to present a definition of LD to clarify the way I use the term. However although I present one of the most widely used and acknowledged definitions here as an operational definition for the purpose of this research, I stress that I feel much like Oliver (1996:103) who states: “...none of the definitions adopted can be shown to be in accord with the experience of disability and none of the practices stemming from these definitions can be shown to work effectively.” Although Oliver is referring specifically to physical disability here, he could just as easily be referring to learning disability.

I have elected to use the definition in the Diagnostic and Statistical Manual of Mental Disorders – fourth edition (DSM-IV) of the American Psychological Association, which states:

Learning disorders are diagnosed when the individual’s achievement on individually administered tests in reading, mathematics or written expression is substantially below that expected for age, schooling and level of intelligence (Thomas, 2000:149, citing the DSM-IV manual, 1994).

This description is usually cited by psychologists in South Africa, but the reality on the ground is that a much looser definition applies. The term “learning disability” as used in South Africa usually refers to children who have average to above average intellectual potential but who present with scholastic difficulty, particularly with regard to literacy. However, I stress *usually*, as there is evidence that there is still confusion and inconsistencies

among and even within the different provinces, and between teachers in rural and urban areas. Teachers in mainstream schools in KwaZulu-Natal who were interviewed by undergraduate students in the discipline of speech-language pathology at the University of KwaZulu-Natal expressed confusion over both the identification and management of learners with LD (Hlela, 1997, Khubeka, 2003). Khubeka (2003) found just over half of the teachers interviewed were, at best, “vaguely familiar” with the term LD. The majority identified family problems and brain damage as causes and suggested it could be identified in a child who looks malnourished or dull. None of the teachers interviewed suggested that a child who has problems expressing him/ herself may have LD and less than half of the teachers suggested that a child with LD may have difficulty following instructions. *Education White Paper 6* (DOE, 2001) refers in broad terms to learners with organic, medical disability having access to special education. As remedial schools existed in South Africa at the time, one can conclude that the implication is that learners accessing remedial schools had “organic, medical disability.”

I return to this issue of how to define LD in Chapter Two. Perhaps if we seek a definition at all it should come from those who know the problem best – the insiders. Oliver (1996:10) cites Wallach Ballagh (1991:38) thus: “[s]ocial theory, coming to terms with social life, means defining, describing, or naming *our* experience, our historical reality *for ourselves* rather than living with definitions imposed upon us” (emphasis mine). Gerber and Reiff (1991), in their interviews with adults with LD, ask them to define LD themselves. Dane (1990:12) supports the view that children with LD define it for themselves. This is a question put to my own research participants which is discussed further in Chapter Six.

To re-iterate, for the purposes of this study, particularly at the outset, I use the term ‘learning disability’ or ‘LD’ to imply all that is described by the DSM-IV classification or categorization. However I intend to challenge this definition

after analyzing the data presented in this report. At this point however I ask the reader's indulgence as I accept the DSM IV definition for pragmatic reasons only, and not because I believe it to be right, good or comprehensive. I intend through the data analysis to show that the children who 'wear' this label define their learning difference themselves.

Life history:

It is also necessary at this point to define the life history methodology, and to describe the way I use this term. It serves as both a methodological strategy (for data collection) and an analytical framework. This refers to how I analyze the ways in which children with LD narrativise their lives. Typically the life history methodology is used with adult participants, and to reflect back over a life lived. One could argue whether children in fact have 'histories.' I have used the methodology to generate a story of a 'life so far' for each of my informants. The context is the education system in which their experiences occur and the central theme of each of their stories is their learning disability. I therefore refer to the learner's history of his/her LD.

Experience:

I am using a Laingian approach to looking at experience. R.D. Laing was steeped in the anti-psychiatry movement of the 1960s. He attempted to illustrate how madness- which in his work refers mainly to schizophrenia- "did not only arise within the individual, but arose as part of a social mechanism" (Jenner, 2001:17). His "existential-phenomenological" view of mental illness is an attempt to see mental illness beyond a disease model (Potter, 2001). Both LD and ADHD are classified in the DSM-IV and by implication are psychological "diseases" or "disorders," and the core of my argument for this research is an attempt to understand LD beyond a disease or pathology model.

Laing (1967) claims "experience is the only evidence". This is resonant with Bruner's claim that "lived experience as thought and desire, as word and image

is *the primary reality*” (Bruner, 1986:50). However according to Laing (1967) I can never know another’s experience; I can observe his/her behaviour and that becomes my experience in the same way that my behaviour becomes his/her experience. In fact Laing goes as far as to suggest that there is no such thing as an “I”- no man is an island –we all impact on one another’s experience and behaviour in a reciprocal fashion (Barbetti, 2001). For me the point being made here is this: the way children with LD experience their LD is always in relation to the reactions, behaviour and expectations of others. In other words no experience occurs in a void. As Laing argues: “...behaviour is a function of experience, and both experience and behaviour are always in relation to someone or something other than self” (Laing, 1967:21-22). He goes on to quote Goffman who says: “There seems to be no agent more effective than another person in bringing a world for oneself alive, or, by a glance, a gesture, or a remark, shriveling up the reality in which one is lodged” (Goffman cited in Laing, 1967:28).

Finally, despite my aim to present the lived experience of children with learning disability, I acknowledge that I can never know another’s experience (Denzin & Lincoln, 2003:51). The best I can hope for are their representations of that experience, which are evident in the stories they tell about themselves.

8. Outline of chapters

I have divided this report into three parts. The three chapters in Part One describe the process or development of this project; Part Two includes what I refer to as the product, the stories that are the result of the process; and in Part Three I present my perception or insight into those stories.

In this chapter I have described the rationale for this research – what got me started on this process of trying to add to an already extremely well researched field. The motivation for this research comes largely from my own background

as a speech-language therapist and therefore I provided a brief biography of myself, a pen-sketch that really only outlines my professional interest in this topic. The more personal interest is, I believe, apparent throughout the report. Oliver (1996:50) says: “personal experience does have a direct, if complex, influence both on what gets written and the way it gets written.” I make no attempt to deny or hide this and throughout this research process and the subsequent writing of the report have “celebrated subjectivity” (Guba, 1990:17). I have also introduced the key arguments for an alternative methodological approach and challenge the hegemony of the logical-empiricism that underpins research in the field of LD.

Before I detail the theoretical framework which reflects my own worldview, however, it is first necessary to review the literature in the field and in so doing identify the gaps and silences in the current literature. In Chapter Two I therefore provide the literature review. I review the literature thematically, focusing on the controversies around defining or describing the phenomenon of LD. I then review the dominant methodologies in the existing research as a way of motivating or providing a rationale for an alternative methodology. I end the second chapter with an identification of what I believe to be gaps and silences. Through the literature review it will become apparent that I do not believe that the gaps and silences identified can be filled by perpetuating the dominant methodological choices. While reviewing the literature I am also positioning my own research in terms of its theoretical and methodological focus. Chapter Three reveals my positioning and the paradigmatic positioning for the research which best resonates with my own world view. My worldview is highly likely to have an impact on how meaning is constructed or co-constructed in this research process and therefore it is necessary for me to declare this at the outset. It is this personal world view or frame of reference which dictates why I set out to “re-search” this field and also dictates to some extent the methodology used. The research design is my attempt to address the gaps and silences identified in the review of the literature, with specific

reference to how the selected methodology fits into the paradigmatic positioning. I use a methodology which is consistent with my worldview.

I present my findings in two ways. In Chapter Four I present the product which results from the data collection process: five narratives, being my attempts to capture the raw data, presented as the stories my informants shared. I am, as a researcher: “not only interested in what [my informants] say, (life history), but also in how they say it [life story]” (Kazmierska, 2004:185). The authenticity of their voices is illustrated in the italicized script, which in each case is a verbatim transcription of interview data.

In the third and final part of this report, formed by Chapter Five and Chapter Six, I present *my* understanding, or my interpretation and perception of that product, in other words the analysis, being the themes I see in the data. This then is where the new theory begins to emerge, and where I begin to answer the critical questions. Finally in Chapter Six as I conclude and draw my argument to a close I summarize my thesis.

9. Limitations

Throughout the research process I was aware of the following **ethical issues** and my attempts to address them may have resulted in **limitations** to the research:

- Insensitive handling of data may cause harm (Scott, 1997:162). The possibility of exploitation and potential power differential between researcher and informants needed to be acknowledged and sensitively handled. It was important not to create “researcher–researched” hierarchies (Cole & Knowles, 2001, Harry, 1996) – especially as the informants were younger than me and could have considered themselves to be from a “socially stigmatized” group.

- It was important to conceal identities of all participants in order to ensure anonymity and confidentiality, so it was necessary to fictionalize to an extent (Burgess, 1995, Cole & Knowles, 2001).
- Informed consent, particularly as informants were children, who need to fully understand the nature of the research and their involvement, (Burgess, 1995) had to be ensured by seeking consent not only from the parents but also from the children who would be the participants. Where access was granted by teachers and/ or parents, this did not imply access has been granted by the informants / children. In addition to this parents/ teachers may have acted as gate-keepers (Burgess, 1995) preventing the children from participating even where they may have wished to.
- Where changes occurred during the process that could nullify informed consent (Harry, 1996) informed consent had to be reviewed

Other limitations relate to the **quantity and quality of data**:

- The amount of information that was shared by informants was dependent on the relationship between the researcher and the informant. This is discussed in detail in Chapter Three.
- There may have been some feelings and experiences informants do not even recognize and were thus unable to discuss. In addition to this memory failures (Bailey, 1987) could have resulted in inaccurate or reduced recall.
- There may have been experiences the informants did not want to share; it is not easy to discuss stressful issues and there may be much, particularly regarding their educational experiences, that the informants find stressful (Lloyd-Smith & Davis, 1995:11). Bailey (1987:177) refers to both deliberate lying and unconscious mistakes made by informants, particularly where there is not enough trust between the informant and the researcher for the informant to feel comfortable sharing sensitive information or painful experiences.

- The deeply personal rationale results in me bringing a strong emotional attachment to the process. I have declared my subjectivity up front, but the difficulty retaining a “rational subjectivity” may also be considered a limitation.

Another potential limitation could be with regard to **access**:

- The sites or schools to which I had access resulted in a limited pool from which to select informants. The result of this is that the informants all came from one area (geographical), the same race, culture, language, and socio-economic group.

In this chapter I have outlined the rationale for this study. I have given the personal and the more “academic” reasons. However strong the personal motivation may have been though, this research really only developed out of a frustration with the literature that seemed lacking, that was not describing the children that I know. It is therefore necessary to review the literature in the field and identify the gaps and silences that proved the true motivation for this research. I do this in the following chapter.

CHAPTER TWO

LITERATURE REVIEW: focusing the lens

1. Introduction

In the previous chapter I described the focus of and rationale for my research, and gave a brief overview of the methodological approach I adopted. Informing this, however, is what I have read in both past and current literature: research that has shaped my own understanding of LD. In this chapter then I present an overview of that research and challenge the apparent hegemony of what I described as reductionist and overly empiricist approaches in the previous chapter. There is a dual focus in this chapter, a focus on content and a focus on methodology. The latter is part of the study's analytical framework primarily because life history is both a methodological strategy and a conceptual framework. In the first part of this chapter the predominant research paradigms in the study of LD are identified and critiqued, leading to the motivation for the present study and the proposed alternative approach to understanding learning disability. In the second part of this chapter I attempt to analyze the current literature in the field of learning disability by "deconstructing the concept to identify the attributes or characteristics, assumptions, gaps, limitations, differing perspectives" (Morse & Mitcham, 2002:7). My purpose is to show how the predominant focus of research in the field perpetuates a fragmented view of LD.

As this is a large and somewhat amorphous field, without clear boundaries, I present this overview of the content of the literature by categorizing it according to area of focus. I present the literature according to the prevalent themes. These are defining LD, managing LD and experiencing LD. I begin this process with a detailed review of research that attempts to define the perplexing phenomenon so loosely referred to as "LD," and attempts to establish exactly what LD is and is not. Subsumed under this is literature that

fragments LD: current research that tends to focus on specific deficits identified as part of the “syndrome” or phenomenon of LD. I refer to this as reductionist in the previous chapter. I therefore review research that focuses on the parts or components of the phenomenon of LD. In the following section I review the literature around management of LD within this reductionist paradigm, in other words the “fixing” of the “faulty parts” of the learner. I include in this latter discussion a brief overview of the inclusive education debate as I return to the issue of inclusive education when presenting my data. It is in presenting my data that the need for a new approach to managing LD will become clear. A key factor in precipitating this change will be an understanding of the way children with LD experience their LD.

As I aim to illuminate what it is like to experience LD, I move towards a justification of the methodological choices I make, by introducing research that looks at experiencing LD. Laing (1967) claims that experience is the only evidence. This is resonant with Bruner’s claim that: “lived experience as thought and desire, as word and image is *the primary reality*” (Bruner, 1986:50). I have introduced the concept of experience: what it is, and how it is defined for the purposes of this research, in Chapter One.

In the final part of this chapter I introduce the concept of identity, and I look at different modes of identity construction. I therefore ask: Is there a LD identity? I focus mainly on how experience is turned into narrative and explore the various ways in which children with LD use narrative conventions to give meaning, value and significance to their varied experiences.

In this way the literature review will reinforce the rationale for my research and move towards the methodological choices made, which are discussed in detail in the following chapter. However it is necessary first to briefly describe the predominant research paradigms, as it is the very dominance of these paradigms that I challenge.

2. Dominant research paradigms: Review of methodologies used in existing research:

The rationale for the present study arose partly out of a dissatisfaction with the themes or the theories being generated by research that is so reductionist and deficit-focused. Despite the wealth of research into the different *parts*, *fragments* or *deficits* identified as part of LD, Riddick mentions "...the area where there is least research at present is on the day to day implications of living with cognitive impairments such as poor short-term memory" (Riddick, 1996:20). The deficit focus is again apparent in this quote. I would like to expand this to suggest that there is minimal research on the day to day implication of living with LD, particularly from the child's perspective. Therefore, a significant rationale for this study is the methodological approaches employed by researchers in this field, which I believe require a challenge.

Methodologically studies to date have been predominantly positivist, empirical and **quantitative**. Scores are computed and compared (Gresham et al., 1996), numbers are counted (Kravetz et al., 1999) and researchers desperately defend their "objectivity." Reason and Rowan (1981:xiv) refer to "quantophrenia" in research in general and suggest that there is "too much counting going on." Certainly this is true in the field of LD research when a perusal of just one of the primary journals, the *Journal of Learning Disabilities*, reveals a strong empirical, quantitative, positivist bias, as indicated in the previous chapter. Quantitative research continues to identify smaller and smaller areas of focus and thus "fragments" learning disability. Kavale and Forness (1996) provide an overview or meta-analysis of the literature around social skills deficits in children with LD, and using quantitative methodology counted up the features of LD identified and researched in other studies. Even attempts to define or describe LD, which common sense suggests should not be "done by numbers," are framed within the traditional quantitative, empirical paradigm.

There is however a growing trend towards the use of **qualitative** methodologies in the study of LD. Qualitative inquiry is used typically when the adequacy of available knowledge is questioned or bias is suspected, according to Morse and Mitcham (2002). It is just such a belief that has led me to seek new ways of understanding LD. As mentioned in the previous chapter, there is still no universally accepted, undisputed definition or understanding of LD. For this reason, quantitative research, if conducted in the positivist empiricist tradition which assumes various “truths” (Higgs & Smith, 2002), may be responsible for perpetuating an incorrect understanding or a *misunderstanding* of the phenomenon of LD. Qualitative research is particularly appropriate for the exploration or even re-examination of phenomena (Morse & Mitcham, 2002). A qualitative research design allows for an insider perspective and is particularly pertinent when the research question can best be answered by looking at personal experiences (Gerber & Reiff, 1991, Morse & Mitcham, 2002:13).

The qualitative methodology that is currently favoured in the literature is the case study. According to Riddick (1996:47) the advantage of case studies and other qualitative methodologies such as life histories, is that a holistic picture emerges from the data. What the case study and other biographical methods allow, is an exploration of the *experiences* of people with LD. Bashir et al. (2000), Edwards (1994), Gerber and Reiff (1991), and Sinclair Taylor (1995) use case studies with different age groups: adults (Gerber & Reiff, 1991), students at a tertiary education institution (Bashir et al., 2000), teenagers in a special school environment (Sinclair Taylor, 1995) and adolescents (Edwards, 1994). These studies and others are critiqued below. However there is a dearth of research in this area, in particular research that considers experiences of learners *as reported by the learners themselves*, rather than by the parents or teachers. Norwich and Kelly (2004) stress the importance of acknowledging the child’s voice in research into issues that impact directly on them. Thus my

study seeks to retrieve the ‘voice’ of children with LD and to uncover strategies of identity construction that may be unique to them.

The diagram overleaf (Figure 3) represents the current and the possible understanding of LD. The top half shows the predominant themes in the literature. It can be seen that the way we understand or define LD feeds into the way it is managed. If however we begin to understand it differently, as represented by the bottom half of the diagram, the way we manage LD or learners with LD will, in all likelihood change. Recent research is beginning to reflect a change in thinking about LD, particularly research that uses the social model of disability as a framework. However I do not believe the existing research goes far enough in changing our understanding and therefore reflect potential new knowledge in the bottom corner of the diagram. I will return to this in the final chapter of this report and discuss that new knowledge and how it potentially transforms the way LD is managed, both within the classroom and by health professionals.

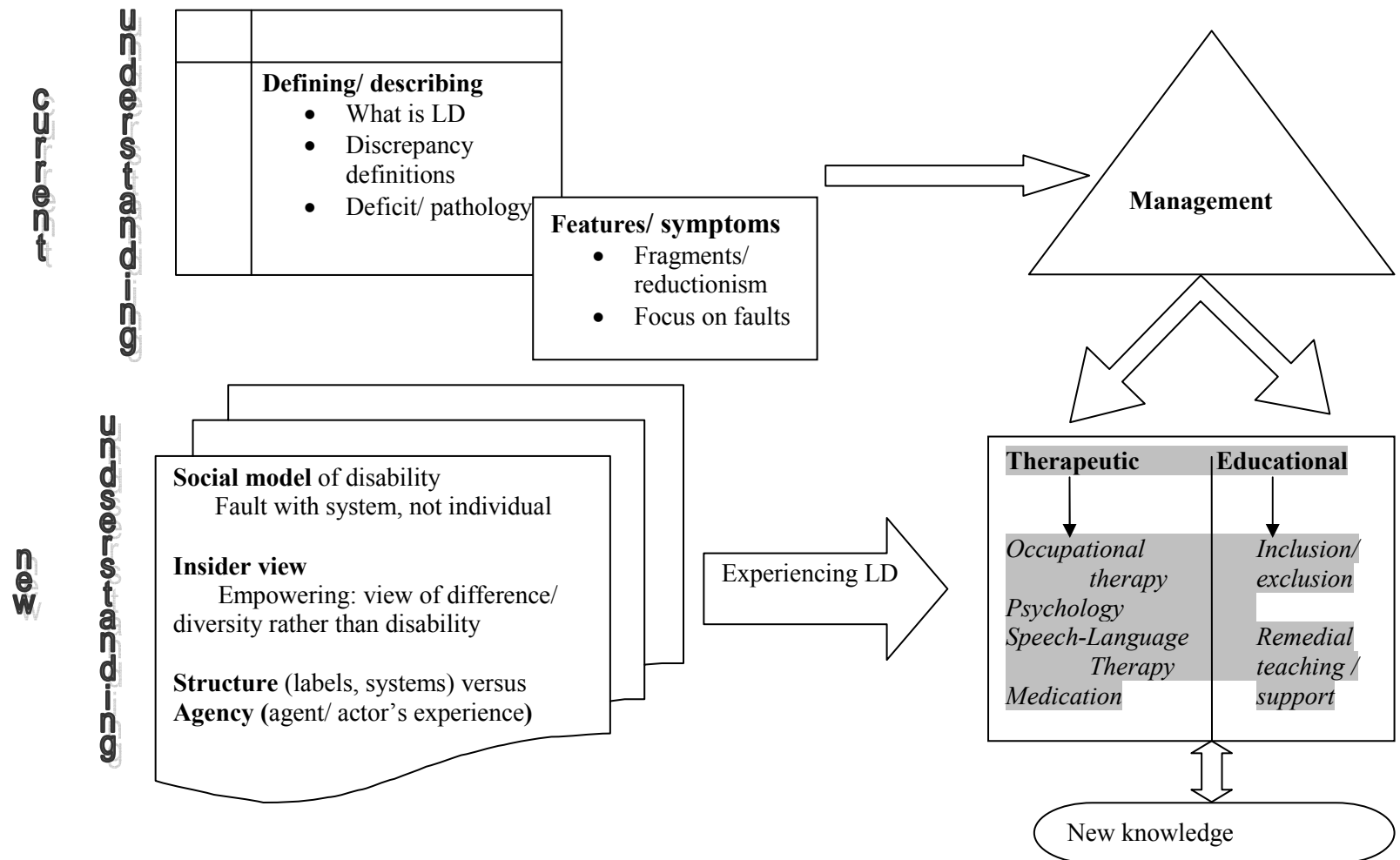


Figure 3: Diagram to show potentially transformed understanding: shaded area represents potentially transformed views

3. Thematic analysis of literature

Before attempting to answer a question on how children with LD interpret their condition, it is necessary to explore what the literature says about LD, about what it is and what it is not.

3.1. Defining LD:

“The invisible disability” (Vaughn et al., 1996 :598), “mind-blurriness” (Frank, 2002:10) and “the LD constellation” (Kavale & Forness, 1996:235) are just some of the many terms used to refer to what is loosely labeled “learning disability” or LD. Discussion about what is and is not LD, who ‘has it’ and who does not, has been described by Sleeter (1987) as an effective sleeping potion. However despite the risk of inducing somnolence, it is a necessary discussion at this point. This is a phenomenon that affects between 5% and 10% of the population, according to Dane (1990:14). The issue of definition is critical to these statistics, as the variation apparent here is a clear indication of the lack of consensus on what actually constitutes LD and who ‘has it.’ Sternberg and Grigorenko (2000:42) state simply but emphatically: “Something is wrong with the way we identify and educate children with learning disabilities.” This is the core of my thesis. If we look first at what is wrong with the way we identify children with LD, then a logical progression is that this will enable us as educators to identify what is wrong with the way we educate them, with a view to changing this.

Attempts to define learning disability range from describing it as a neuropsychological condition (Kravetz et al., 1999, Morgan et al., 2000) to the suggestion that it is merely a socially constructed notion (Sleeter, 1986). Some critics go as far as to suggest that “learning disability” is merely a myth, it does not exist (Kaplan et al., 2000, Kavale & Forness, 2000) and others doubt whether it can or even should be defined (Dane, 1990, Sleeter, 1987, Sternberg & Grigorenko, 2000).

I believe that there are currently two significant issues that cloud our understanding of learning disability. These are that there is a lack of consistency in terminology and there is little consensus on what actually constitutes a 'learning disability.' Dane (1990:7) suggests "the development of a sound knowledge base has been, and continues to be, exceedingly difficult" due to the lack of agreement on what LD is and who 'has' it. The problem is the lack of "clear and consistent criteria for identifying LD children" (Sternberg & Grigorenko, 2000:23) which results in apparently conflicting research findings and difficulty replicating research, as research subjects or participants are not all selected using the same criteria.

Terminology has changed over the years. Less than a century ago the words 'feeble-minded' and 'defectives' were used to describe a wide range of "troublesome scholars" (Bennison, 1987). In the 1950s, the term 'minimal brain dysfunction' was used (Carrier, 1987), hardly less derogatory but which articulates quite clearly the contemporary understanding of the etiology if not the nature of learning disability.

The creation of a label and a "disability" to explain poor scholastic performance was viewed by some as politically expedient (Carrier, 1987, Dane, 1990, Sleeter, 1987). The 1960s was the decade of the space race and rapid technological change. In the United States politicians needed an explanation for poor performance of learners, particularly in the areas of mathematics and science, which did not reflect negatively on the education system itself. In addition to this the growing middle class, where parents had high expectations for their children, were provided with a more palatable explanation of their child's underperformance than that the child was 'dull' or 'feeble minded.' Parents could accept that their child was in fact bright, but had a specific problem or disability that could be resolved with the appropriate educational intervention. These parents played a significant role in shaping learning disability theory at the time (Carrier, 1987). Sternberg and Grigorenko (2000:4) add their voices to the argument that this is a socially constructed notion by suggesting that a society that

values some skills more than others dictates who is considered “disabled.” Furthermore they suggest “where and when a child is born has a tremendous impact on whether the child will be labeled as having a learning disability” (Sternberg & Grigorenko, 2000:5).

During the late 1960s and 1970s there were many attempts to generate a definition of LD, including those of the *National Joint Committee on Learning Disabilities* (NJCLD) and the *Education for all Handicapped children Act of 1975* (EHA PL 94-142) (Dane, 1990). Early definitions such as these suggested a breakdown in the “psychological processes” and refer only to a language- based difficulty. Rosenthal, in the 1970s (cited in Edwards, 1994:11) referred specifically to *cognitive dysfunction* involving the organization of graphic symbols, a very narrow definition but one that nonetheless implied an intrinsic basis. The use of words such as “imperfect ability,” “brain injury,” and “brain dysfunction” in the EHA definition indicate the influence of the deficit or pathology model. At this time specific learning disability was understood as a processing problem (Kavale & Forness, 2000). Early definitions too suggest that this was a homogenous group, but by the 1980s the heterogeneous nature of the group was beginning to be acknowledged in definitions. By the early 1980s the most widely accepted definition was that of the NJCLD:

Learning disabilities is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition of listening, speaking, reading, writing, reasoning and mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction (Ratner & Harris, 1994:186)

This definition suggests the problem is “intrinsic to the individual,” and is due to a “presumed central nervous system dysfunction,” both of which again imply a pathology focus. The exclusion once again was that this might be *concomitant* with “other handicapping conditions” but that the learning difficulty was *not due* to these same conditions. However, it is

difficult, if not impossible, to draw a line between learning difficulties that may be as a result of “other handicapping conditions” such as sensory hearing loss, cerebral palsy, auditory processing disorder or even environmental deprivation.

It was also in the early 1980s that the term ‘learning disability’ found its way into the third edition of the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM III) and more recently the DSM-IV⁸ with the focus on “psychological characteristics,” or fragments, parts, symptoms. By virtue of being listed in the DSM III, LD became an ‘illness.’ The excessive use of words such as “mental disorder,” “dysfunction,” “impairment,” “disability” and “deviant behaviour” in the DSM III and its successor, the DSM IV (currently in use), clearly signals the influence of the medical paradigm on any attempt to classify what essentially are behavioural differences. In fact Barbetti (2001) suggests the DSM III and subsequently the DSM IV “mov(ed) psychiatry closer to mainstream medicine, hence closer to legitimacy...,” a view held by Carrier (1987:47) who suggests that by describing the basis of LD as mild neuropathology it gives the diagnosis legitimacy. The reference to the legitimacy of mainstream medicine indicates the hegemony which has underpinned our understanding of LD to date. However the medical approach is too narrow to help us understand or illuminate psychological differences (Barbetti, 2001), which in essence is how LD is viewed by many. It is noted though that there is a swing in some research back towards the ‘medicalization’ of LD (Bigler et al., 1998) again an indication that if it is recognized as such it gains legitimacy and with it the research funding, additional resources and support for learners, amongst other things. A medical diagnosis makes this a ‘real problem’ requiring ‘real intervention / management,’ or to put it more bluntly, medical attention!

⁸ “Learning disorders are diagnosed when the individual’s achievement on individually administered tests in reading, mathematics or written expression is substantially below that expected for age, schooling and level of intelligence (Thomas ,2000:149 quoting from the DSM-IV manual, 1994)

Clough and Thompson (1987:145) refer to true LD as being as a result of “in-child excuses,” a clear reference to the inherent nature despite the negative connotation of the word “excuses.” Frank (2002:10) too takes a stand on the “intrinsic vs. extrinsic” debate. Although he uses the term ‘dyslexia’ his definition of dyslexia is almost a paraphrase of the DSM IV definition of LD. He states that LD is a language problem with a *neurological basis* that affects reading, listening, spelling, writing, speaking and memory. Thomson (1990) supports the neurological basis by citing Hirshelwood’s finding that dyslexia has as its basis the *activity of the angular gyrus* (Thomson, 1990:4), a view supported by Shaywitz’s finding of *greater activity in Broca’s area* (cited in Frank, 2002:13). In addition to this there is research evidence that suggests a genetic link (Dane, 1990, Dykman, 2005) as well as specific pre-, peri- and post-natal risk factors similar to risk factors for other congenital conditions. These factors include alcohol abuse or smoking by the mother during pregnancy and low birth weight (Dane, 1990). The suggestion that LD is, or could be, a congenital condition further underscores the “intrinsic” nature.

The definition has also evolved over time to include previously excluded categories. The early definition expressly excluded children who had learning problems as a result of “environmental, cultural or economic disadvantage” (Dane, 1990). However in South Africa, with so many children not even being educated in their mother tongue, these very issues (economic disadvantage, cultural difference and environmental deprivation) are likely to impact on a child’s classroom performance and even lead to scholastic failure (DOE, 2001).

There seems to be broad areas of agreement across definitions, and through the evolution of the definition at least three factors have been consistently mentioned:

- that LD has an intrinsic basis even where extrinsic factors may exacerbate this,

- that there is a discrepancy between the potential and performance in at least one of a number of specified areas,
- and that the weakness/ failure/ problem occurs in academic areas (Sternberg & Grigorenko, 2000:21), such as listening, reading, comprehension, written language, arithmetic and mathematics (Sternberg & Grigorenko, 2000:5).

It is now accepted that the term ‘learning disability’ or ‘LD’ is an umbrella term used to describe a heterogeneous group of conditions, (Gearheart et al., 1988) all of which may have a similar symptom, which is scholastic underachievement or failure that does not seem to be as a result of either sensory or cognitive impairment. In most cases this underachievement refers specifically to reading, according to Sleeter, who views the label “learning disabilities” as “a catch-all for unexplained low achievement” (Sleeter, 1987:70).

The controversy around defining LD continues unabated, with different aspects being focused on by different experts (Edwards, 1994:9). Furthermore, recent research is differentiating between language learning disability (LLD) and nonverbal learning disability (NVLD) where previously the focus was on the *language* disability (Kimbrell and Karnes, cited in Edwards, 1994) and *lower performance on verbal tasks* than nonverbal tasks (Badian, cited in Edwards, 1994). Even the appropriacy of the term ‘LD’ is still debated, with education policy documents referring in much broader terms to “learners with special educational needs” (LSEN) and, more recently, “learners with barriers to learning” (DOE, 2001). Thomson (1990) uses the term ‘barriers to learning’ to include both intrinsic and extrinsic factors. However he suggests a cognitive basis to what he terms dyslexia, described overleaf. Sternberg and Grigorenko (2000) state that LD is best explained as an interface between both intrinsic and extrinsic factors. Stanovich (1999) goes as far as to say: “the term ‘learning disability’...is redundant and semantically confusing” (Stanovich, 1999:350), in other words the term itself bamboozles us. This confusion

possibly arises because many professionals working within the field of LD are using the term to mean different things.

The field of learning disability is a field that, due to its nature, is researched from the perspectives of many different disciplines, such as psychiatry, psychology, neuropsychology, education, speech-language therapy and occupational therapy. Although this results in a wealth of research and therefore knowledge about LD, one disadvantage of the proliferation of research in this field, from so many different disciplinary perspectives, is that each profession brings a different understanding of the notion of learning disability to their research (Archer & Green, 1996). Each field attempts to: “understand how its fragment of the universe works” (Lewis, 1998:19). Compounding the problem is the use of the terms ‘learning disability,’ ‘specific learning disability’ and ‘dyslexia’ as synonymous by some authors and as representative of different disorders by others⁹ (Edwards, 1994, Heaton, 1996, Reid, 1994, Riddick, 1996).

Initially the coining of the term ‘learning disability’ seemed to allow parents and learners to avoid the stigma of retardation or brain damage inherent in previously used terms such as ‘feeble-minded’ and ‘minimal brain damage’ (Bennison, 1987; Carrier, 1987). However the term ‘learning disability’ then implied *disabled*, which was just as stigmatizing. Dane (1990:9) suggests that parents possibly elect to use the term ‘dyslexia’ as it does not have the same connotation or inference of disability. Riddick (1996) differentiates between the terms ‘specific learning disability’ and ‘dyslexia’ by suggesting that psychologists use the former term and lay people and clinicians tend to use the latter term. However she does not identify who she refers to as “clinicians” and how she reaches this conclusion. It is suggested that the term ‘dyslexia’ is less stigmatizing as there is no reference to *disability* (Archer & Green, 1996). It is no wonder when popular media reminds parents and learners alike that Tom Cruise,

⁹ The term ‘learning disability’ will be used consistently in this report except where the author being quoted uses another term. The abbreviation ‘LD’ will be used for ease of reading.

Jamie Oliver, Vince Vaughn, Whoopi Goldberg, Princess Beatrice and Richard Branson are possibly dyslexic¹⁰ The label is almost trendy! Catts and Kamhi (1999) differentiate between dyslexia and language learning disability (LLD) by suggesting that although both present as difficulty with reading and written language, in the former case reading comprehension is good whereas with LLD reading comprehension is poor. Frye, cited in Edwards (1994:9) suggests that there may be approximately 1000 possible terms that can be used to describe specific learning disability which is also, in the same reference, termed dyslexia!

Furthermore the meaning of the term 'LD' changes in different geographical contexts. In the United Kingdom, the terms 'learning disability' and 'learning difficulty' may be used to describe scholastic difficulty resulting from mild or moderate cognitive impairment. Contrary to the above definitions from the DSM –IV and the NJCLD, the definition used in the “*Signposts for Success*” document from the Department of Health in the United Kingdom states that learning disability is usually described as:

... significant impairment in the intelligence and social functioning acquired before adulthood... People with learning disabilities may also have autism, communication difficulties, epilepsy, memory impairments...up to 30% of people with learning disabilities have associated physical disabilities most often due to cerebral palsy...about 30% of people with learning disabilities have a significant impairment of sight and 40% have significant hearing problems...many people with learning disabilities have little or no functional speech.
(<http://www.northumberland.gov.uk/LDspec.asp>, 2002)

In fact in the United Kingdom's *Code of Practice on Special Educational Needs* there are four definitions of learning disability (Booth, 1998) and the term 'dyslexia' is used to refer to that group of children who “despite conventional classroom experience fail to attain the language skills of

¹⁰ <http://www.greatschools.net/cgi-bin/showarticle/2258#entertainers>

reading, writing and spelling commensurate with their *intellectual abilities*” (Edwards, 1994:5, citing Stirling, 1978). This is re-iterated in Thomson’s definition of dyslexia as:

...a severe difficulty with the written form of language independent of intellectual, cultural and emotional causation. It is characterised by the individual’s *reading, writing and spelling* attainments being *well below the level expected based on intelligence* and chronological age. (emphasis mine) (Thomson, 1990:4)

When compared to the NJCLD and DSM IV definitions of LD, the parallels are clear.

In the United States and Canada the term ‘learning disability’ usually refers to scholastic underachievement that cannot be explained by sensory or cognitive impairment, as articulated in the definition proposed by the NLCLD (discussed above) and the Diagnostic and Statistical Manual of Mental Disorders–fourth edition (DSM-IV), of the American Psychological Association (APA), presented in Chapter One but repeated here for ease of reference:

Learning disorders are diagnosed when the individual’s achievement on individually administered tests in reading, mathematics or written expression is substantially below that expected for age, schooling and level of intelligence (Thomas, 2000:149 citing the DSM-IV manual, 1994).

In Spain, LD is viewed as on a continuum somewhere between sensory, motor and cognitive impairments, which are considered “permanent deficits,” and what are referred to as “transitory deficits” (Jimenez Gonzalez & Hernandez Valle, 1999:267). The latter seems to refer to a vague category of problems that can be remediated within the mainstream classroom. In other countries, such as New Zealand, Germany and Mexico: “LD ...is not considered a category of special education” (Jimenez Gonzalez & Hernandez Valle, 1999:273).

In any of the above definitions that imply a discrepancy between potential and performance, the potential is typically judged by the intelligence quotient, or performance on an IQ test. Gresham, McMillan and Bocian (1996) differentiate clearly between low achievement despite “potential” as measured by an IQ score (LD), low achievement where there is no indication of additional potential (LA) and mild cognitive impairment, identified by low IQ. What is interesting is that none of these differentiations can be made without reliance on IQ tests and other standardized measures. In other research that uses IQ test scores, McMillan Gresham and Bocian (1998) also categorize learners into those with LD and those with cognitive impairment in order to comment on school referral policy. Olfiesh and McAfee (2000) found a heavy reliance on IQ test scores, not only in identifying LD but also in planning intervention. Yet 70% of their participants or respondents were not happy with the tests used. The use of IQ tests and other standardized measures is heavily criticized and rejected in current research (Bailey, 1998, Elution et al., 2000, Gregg & Scott, 2000, Siegel, 1999, Stanovich, 1999, Sternberg & Grigorenko, 2000). Stanovich (1999:351) and Sternberg and Grigorenko (2000) are scathing in their rejection of the IQ score and IQ tests in general as tools still used in the identification of LD; and Stanovich even refers to “IQ fetishism.” Sternberg and Grigorenko (2000:64) are clear about their position that “IQ has no place at all in the diagnosis of LD.” Siegel (1999:311) suggests:

It is a paradox that IQ scores are required of individuals with learning disability because most of these people have deficiencies in one or more component skills that are part of these IQ tests; therefore their scores on IQ tests will be an underestimate of their competence.

Since the move towards inclusive education in South Africa, and the publication of *Education White Paper 6* (DOE, 2001), there has been much rhetoric around assessment or evaluation and particularly IQ testing. Despite policy recommendations that IQ testing is abandoned in SA and even categorical statements by politicians that it no longer occurs (Naicker, 2002:77, Savitz & Jansen, 2005), my current experience is that the IQ test

is alive and well in the changing South African education system. We still rely on IQ scores in our decisions regarding appropriate placement. Whether this is to a specific class in the mainstream environment or to a specialized educational environment, placement is based on the child's response to various subtests on a standardised test battery. Tests are translated and declared "culturally valid." The child is put in a room with a stranger who may even assess him/her in a second language. Based on the child's performance under these circumstances judgments are made that will shape his future. Radebe (2003) and Wallis and Birt (2003) discuss some of the complexities of assessing a learner. Culture-fair tests do not exist in all official languages. Moreover in some contexts it may not be in the learner's best interests to assess him/ her in mother-tongue. Furthermore, according to the Psychological Association of South Africa (PASA) the educator/ practitioner administering the test should be proficient in the language of the test (Radebe, 2003). Poon –McBrayer and Garcia (2000) raise the issue of assessing children in language that is not their mother –tongue, using tests that are not culture – fair, and refer to the dangers of "school-created learning difficulties" that can arise as a result of inappropriate use of standardised tests and school contexts that do not allow for "culturally diverse learning styles" (Poon-McBrayer & Garcia, 2000).

Using a discrepancy definition of LD (i.e. discrepancy between classroom performance and potential as measured by an IQ test) disadvantages children who are not proficient in the language in which the test is administered. The IQ score may therefore appear to be low due to the fact that the child is being assessed in a language in which he is not proficient. This 'reduced IQ' then may suggest that she is performing to her 'potential' when in fact assessment in her mother tongue would suggest a much higher 'potential.' Sternberg and Grigorenko (2000) propose that regardless of what the subtest of the IQ battery purports to test, it is in all likelihood a measure of the child's vocabulary.

Regardless of language proficiency there is the issue of cultural validity. Most commonly used IQ tests are drawn up to focus on very specific areas which typically reflect values of middle class, White, Eurocentric or American culture (Sternberg & Grigorenko, 2000). Children from outside this group then may perform poorly on the test and do not achieve an IQ score that would suggest good 'potential'; their classroom failure is put down to 'low IQ' or even 'cognitive impairment.' Support then remains reserved for White, middle class children whose test performance suggests 'good potential,' perpetuating the myth that LD is just a White, middle class excuse for poor performance. This is particularly relevant in the South African multicultural, multilingual context where diversity is embraced everywhere but in the tests we use. The lack of culturally appropriate assessment tools extends way beyond educational assessment.

With any standardized test or tool, there is an expected or required response in order to score. There is little or no margin for a tester to use his or her discretion. By virtue of the fact that the test is standardized, there can be little room for flexibility in terms of interpreting results. As a result a child can be penalized for giving what may well be a correct response given his context and culture, but that is not what the test designers considered "correct" (Sternberg & Grigorenko, 2000:54) rendering the ultimate score relatively meaningless. Wallis and Birt (2003:184) recommend what they call "relaxed criteria" for marking responses given by test respondents in a second language. Although in their research they used a personality assessment tool, the issue of testing in a second language still applies to this argument. In their findings there was a significant difference in test scores achieved by respondents when marked strictly, according to test criteria, and when marked more subjectively, where responses were judged to be correct or appropriate even though they were not the responses required by test standardization.

Here I am not referring only to the IQ tests – speech- language therapists, occupational therapists, remedial teachers are guilty of the same thing.

What I wish to stress is that although health professionals are talking one language, although we are reading policy documents that say one thing, although we are admitting “transformation,” the reality is that very little has changed. Sternberg and Grigorenko (2000:8) suggest “we know what to do, we do not do it.” There is a clear divide between the official perspective (policy), the espoused perspective (what we say we do); and what we actually do (Pillay, 1997). I do not intend to explore the reasons for this. Suffice it to say that perhaps we feel more secure pulling out a test manual that tells us exactly what to say and do next and then gives us a neat score after a relatively short period of time. Perhaps that is unfair – perhaps it is fairer to say we still do what we always did but we do it with a conscience – we use our tests fully aware of the problems, holding onto them perhaps more for our own security than for the benefit of the learners we see.

While we talk inclusion, while we talk continuous and classroom based assessment, the first thing we do when we are faced with a child who is not performing is reach for the IQ and other standardized tests! The reality is that there is still a demand for the rather questionable test scores by many of those involved in the management of these learners, for example psychologists, speech-language therapists, paediatricians and even teachers. Most attempts to manage a child with a learning difference still starts with a requirement from the school – be it mainstream or ‘specialized education’- for an intelligence quotient (IQ score). Even in an inclusive setting a child may be moved to a ‘special class’ because of his IQ score (Radebe, personal communication, 2004¹¹). The injustices of this are multiple: the child may not necessarily be a good test candidate, the nature of the test, the situation, the process, the environment, even awareness of the family’s anxiety about testing and the consequences of test results can all impact on performance to some degree (Dane, 1990:54).

Furthermore, standardized tests are sometimes selected with a specific purpose in mind. Sternberg and Grigorenko (2000:54) even refer to “the

¹¹ S. Radebe, Educational Psychologist

testing game.” The selection of assessment tools such as standardized tests allows for an educator or health professional to manipulate labels by, for example, selecting specific tasks or continuing to administer tests until a score is obtained for a specific purpose, such as labeling a child in order to access appropriate services. In my own experience this is not unusual. The selection of tests is sometimes based on the type of results the tester feels would get the child the appropriate intervention. The assumption from the tester may well be that this is in the best interests of the child, but it borders on unethical conduct nevertheless. Levine (2002:14) states:

Adding to the tortuous trails they navigate, many struggling students have been seriously wounded by the current testing mania in our society. Their intellectual identity has been shrunk down to a list of examination scores that will determine their destinies while shedding little light on their true strengths, weaknesses and educational needs.

An additional conflict arises over the so-called “LD/gifted” child, the one who according to discrepancy definitions is not performing at the level expected given her IQ, but who is *not* failing to cope scholastically. Such children might even be presenting as average achievers, but have IQ scores in the superior range. They are described by Sapon-Shevin (1987:182) as “gifted pseudoachievers.” Discrepancy definitions would label them LD: failing to achieve to their potential even though they are achieving adequately for grade. There are also those learners where the gap between potential and performance as measured by IQ and performance is so great that, despite well above average IQ scores, they are failing to cope at grade level. This group is described by Daniels (cited in Sapon-Shevin, 1987:182) as ‘gifted’/learning disabled, or LD/GT; children who: “have problems with language conceptualization, deficits in memory, sequencing, spatial perception and perceptual-motor integration...” (Sapon-Shevin, 1987:182). She goes on to say they are also described as having:

high reasoning and verbal abilities, areas of specific talent, discrepant verbal and performance abilities [as measured on standardized IQ tests], visual perceptual/ fine motor

difficulties, attention deficit disorders, slow response time, difficulty shifting activities, poor organizational skills deficient or uneven academic skills, perfectionism and low self-esteem, ... easily discouraged, inflexible, quickly upset and vulnerable in social relationships (Sapon-Shevin, 1987: 182-183, citing Cordell and Cannon, 1985:144).

The use of the discrepancy criterion in a child with a high IQ is questionable. A discrepancy between ‘potential and performance’ does not mean the same in terms of ability to cope scholastically for the child with a large discrepancy but a high (above average or superior range) IQ score and a child with a smaller discrepancy but an IQ score at the lower end of average or below the average range (Sternberg & Grigorenko, 2000). The latter child is the one who would need additional support or intervention by the remedial specialist, speech-language therapist and/ or occupational therapist.

The “Flynn effect” (Sternberg & Grigorenko, 2000:35) suggests IQ scores have risen since the 1960s. This is possibly why it *appears* that there are more children being diagnosed or identified as LD, and why, in my practice, I am seeing more children with the “LD/Gifted” label. Where the discrepancy definition is applied in a context of the Flynn effect, the gap between ‘potential’ as measured by the IQ score and ‘performance’ would also be widening.

A final comment on the use of the IQ score must make reference to the contemporary thinking about multiple intelligences. If all intelligences are assessed or measured, and a discrepancy is found between potential and performance in an area such as musical intelligence or artistic intelligence, it is unlikely that such a child would be labeled as having a ‘learning disability’ because of what is valued in the way children are educated (Sternberg & Grigorenko, 2000).

While the discrepancy definitions, which suggest that there must be a discrepancy between achievement and potential for a child to be diagnosed

LD, are being hotly contested in the literature, some researchers take another tack and suggest exclusions, in other words what should *not* be diagnosed as LD. Their definitions range from those that exclude cognitive or sensory impairment (Gearheart et al., 1988:270-271) to those that suggest that no child should be identified as learning disabled unless he/ she is failing to cope scholastically (Gordon et al., 1999). However Rosenthal, in the 1970s, cited in Edwards (1994:11), referred specifically to *cognitive dysfunction* involving the organization of graphic symbols as a feature of LD, which clearly conflicts with these 'exclusionary' definitions.

There are alternatives to the discrepancy definitions which do not require one to establish "potential" by an intelligence test of some sort. Because LD in Spain is viewed as a continuum, identification does not require that the child's 'potential' be established. The comparison is made between the individual and his peers in the classroom. A "difference between the achievements of the students and the rest of the class in regard to instrumental learning (reading, writing and arithmetic)" is all that is required for LD to be identified (Jimenez Gonzalez & Hernandez Valle, 1999:269). Another completely different approach to identifying LD is proposed by Miles (1996) who advocates using what he refers to as a "personal" approach to those with what he calls "dyslexia." Such an approach is: "based on experiences of individuals rather than one involving systematic comparisons of dyslexics and controls" (Miles, 1996:112), a clear criticism of using test scores or discrepancy /deficit focus.

Further confusion arises as there is a difference between the legal and the clinical definitions of "learning disability" (Gordon et al., 1999) and there is a discrepancy between policy and practice with regard to diagnosing LD (MacMillan et al., 1998). Sleeter (1987) too suggests that definitions are one thing, practice another. In her research she found that teacher referrals had little to do with definitions of LD but were made on the basis of the child's behavior in the classroom. She goes as far as to describe the "real LD child" as a low achiever with behaviour problems (Sleeter, 1987:74).

Once again the debate is -what constitutes “low achievement” and how do we measure it?

This raises another point that is debated in the literature as there is little agreement on whether LD implies delay or deviance. Snowling, in Riddick (1996) suggests both are possible and constitute different groups of the LD population. If however a discrepancy definition of LD is used, that is by referring to a discrepancy between potential and performance, usually the estimated potential as measured on an IQ test is assumed to be at least within the average range (Riddick, 1996). There is no consensus though on what degree of difference is to be considered a discrepancy (Dane, 1990, Sternberg & Grigorenko, 2000).

However, perhaps too much has been invested in trying to define or describe the phenomenon of LD. Sleeter (1987) goes as far as to say we’re barking up the wrong tree in trying to define LD; that in fact it is not a problem with the child at all but a problem within the system in which the child is being educated. This is my own view, as alluded to previously, and one I aim to develop in my data findings. There is a growing acknowledgement that there are multiple ways of knowing (Eisner, 1990, Phillips, 1990) and a recognition that schools need to: “acknowledge and value different ways of learning and diverse forms of thinking” (Eisner, 1990:100).

The issue of co-morbidity is a further confounding factor. LD can, and often does, co-occur with Auditory Processing Disorder (APD), Attention Deficit Disorder (ADD) or ADD with hyperactivity (ADHD). While the former will not be discussed in any detail here, the latter has relevance for my study and it is therefore necessary to briefly discuss ADD/ADHD. The co-morbidity of LD and ADD is well documented in the literature (Johnston, 1991, Mayes et al., 2000, Neven et al., 2002). The actual extent of this overlap is difficult to determine, due largely to differing definition of LD, as discussed above in section 3.1, as well as the equally vague and

subjective criteria for identifying ADD. Connor (2005) suggests a conservative 25% of children with LD who also have ADD but alludes to figures anywhere between 10% and 92%. Some researchers suggest LD and ADD should be understood as two separate disorders that can co-occur, whilst others suggest these are “overlapping spectrum disorders” (Connor, 2005, Mayes et al., 2000) or even that they should share one diagnostic label (Dykman, 2005). Historically the two conditions (LD and ADD) have shared the label “minimal brain dysfunction” (Riccio & Jemison, 1998). In my own experience teachers tend to use the two labels interchangeably. That ADD is likely to impact on academic performance is logical. In fact for the diagnosis to be made, according to the DSM IV criteria, either social, academic or occupational functioning must be impaired as a result of the impulsivity. Given that a child’s occupation *is* his schooling (Lavoie, 1999), academic functioning is the area most likely to be affected.

ADHD is diagnosed more frequently than any other psychiatric disorder in children (Diller, 1998:15, Neven et al., 2002) In fact Diller (1998:77) refers to an “ADD-ogenic culture.” The reality is that approximately 10 % -15% of children in some schools are diagnosed as having ADHD (Accardo & Blondis, 2001, Diller, 1998). ADHD is described in the DSM-IV as either inattention or hyperactivity-impulsivity that causes “clinically significant impairment in social, academic or occupational functioning” in at least two settings or contexts and where symptoms were first noted prior to the age of 7 years (Neven et al., 2002:148-149). In addition to this, specific symptoms are listed and exclusions are given. The DSM-IV lists three subtypes: predominantly inattentive, predominantly hyperactive or combined type (Fonagy et al., 2002), whilst Amen (2001) extends this to six subtypes. This is only one of many parallels with LD: the definitions *describe* behaviours, rather than *defining*, and both definitions say what the condition is *not*, in other words provide exclusions.

Diller (1998) criticizes these criteria as vague and subjective and decries the lack of a definitive marker for ADD/ADHD. He refers to the use of these

criteria as resulting in “the symptoms [being] the disease.” There are those who believe ADHD is a myth, a “disordering” of normal behaviour invented by the medical fraternity in order to have a legitimate reason for the prescription of drug treatment (Baughman, 2006, Strydom & du Plessis, 2001). Hartmann, in a scathing attack on the medical fraternity, states: “essential to the success of the exploiters is the concept of sickness.” (Hartmann, 1999:xxix). The requirement that the diagnosis is made only by medical practitioners, is criticized as a reinforcement of the simplistic view that this is an “illness, disease or malfunction” or a problem within the child, when in fact any number of factors could be responsible (Neven et al., 2002:4).

Hartmann presents a much simpler view: “ADD is more clearly described as a person’s difficulty focusing on a single thing for any significant period of time” (Hartmann, 1999:xiii). He describes these children as hunters in a farmers world – children with specific strengths, who are geared / wired (Levine, 2002) for a different way of learning. Both Hartmann and Levine are proponents of “the problem is not the child but the system” approach; both suggest changing the system, changing the educational approaches with these children rather than trying to change the children. Note how similar this view is to those of many researchers regarding LD (Booth, 1998, Dane, 1990, Levine, 2002, Lewis, 1998) as discussed above.

Neven et al. (2002) suggest that ADHD occurs more frequently in lower-socio-economic groups. However this is not a view supported in all the literature, where the prevailing view is just the opposite. Researchers suggest discrepancies between rural and suburban schools ranging from 2% of the school population in the former and between 6 and 11% of the school population in the latter (Doherty et al., 2000). Certainly research suggests that the diagnosis of ADHD is prevalent in the white, middle class population group (Kendall & Hatton, 2002) and this seems on the surface to support the argument that it is a myth. However Accardo and Blondis (2001) suggests that the lower reported incidence of AD/HD in African-

Americans is possibly related to “fiscal concerns.” I would suggest that in the South African context at least this could also relate to poor access to health care as well as different priorities across the socio-economic divide. The reality in South Africa is that nearly 15 years into democracy, poverty is still a major problem and equal access to both medical care and education remains a goal, rather than an achievement.

That there are differences in what would be viewed as acceptable behaviour across cultures is indisputable (Fonagy et al., 2002). However if we take this to its logical conclusion, it can be one of the reasons why the diagnosis of inappropriate behaviour appears more in certain cultures than in others. It can also explain why so many research findings appear contradictory, and why Hartmann can conclude: “ADD is a disorder defined by and unique to our culture” (Hartmann, 1999:38).

Evidence is beginning to suggest that not only is ADHD a real condition, but that there are genetic markers for it even in utero (Accardo & Blondis, 2001). However there are as yet no “universally accepted biological markers” (Neven et al., 2002:14). There is an emerging hypothesis, strongly supported by research, that ADD has a neurological basis (Dykman, 2005) and could be the result of an insufficiency of dopamine in the frontal lobes (Hartmann, 1999). Preliminary findings suggest that boys with ADHD have a small prefrontal cortex, caudate nucleus and globus pallidus (Neven et al., 2002, Watkins, 2006). ADHD has even been described as:

..a condition that appears to operate on the boundary between brain function (the realm of neuropsychology and neurology) and the child’s emotional and social relationships within the family and the outside world... (in other words the psychodynamic) (Neven et al., 2002:11)

Perhaps the discussion around defining, whether LD or ADD, is focused too much on labeling. Neven et al. (2002) suggest that the “labeling” of

ADHD serves expressly to suppress nonconformity. I question the purpose and value of labeling a child – questions raised by Ainscow as far back as 1979 (Ainscow & Tweddle, 1979). Sternberg and Grigorenko (2000:9) stress that “labeling is not tantamount to understanding” and furthermore that this is a highly subjective process. Dane (1990:10) too questions the purpose of labeling. However although I agree that this can be abused, I disagree when Dane calls for “rights without labels.” One has to question then how the child will access the support or services s/he has the right to if some form of labeling or identification process does not occur first. This is key to the inclusive education debate: every child has the right to the least restrictive educational environment (DOE, 2001). Yet the determination of what the least restrictive environment will or should be cannot be made without fully understanding the support the learner may need. It is therefore necessary at some point to provide a description of the child’s specific difficulties, strengths, weaknesses and at some point that is likely to be encapsulated into a label or “diagnosis.” Sternberg and Grigorenko (2000) describe the process of labeling as “a lottery.” Bailey (1998:47) agrees that labeling has little functional value because the following are not described by the label ‘learning disability’: “...the child’s intellectual strengths, ...motivation or interests.” Miles (1996:120), too emphasizes the need to see the child’s strengths:

It is now recognized that there have been many highly gifted and creative individuals...who, in spite of their talents, had some degree of difficulty with literacy and language. This does not mean that every dyslexic person has special talents, but it underlines *how mistaken it is to focus simply on the weaknesses of dyslexics rather than recognizing both their weaknesses and strengths.* (emphasis mine)

It is exactly this that has motivated this research – the need to see the child beyond the deficits.

An alternate view may be provided if we look at how the child with LD defines or interprets his/her condition his/herself, or his/her self-

representation. The ideal way to do this, I believe, is to look at how his/her identity is constructed. According to Tice and Wallace (2003) we see ourselves as we *think* others see us. They go further and suggest we see ourselves as we think our significant other persons see us, including parents, siblings, peers and teachers. I am interested in how the child thinks his/her teachers and class mates in particular see him/her if s/he is in an environment where s/he is constantly failing to match up to his/her peers. However, before discussing the notion of an 'LD identity' it is necessary to review the literature that focuses on the failure and on the deficits, which I refer to as fragments of the phenomenon of LD.

A significant portion of the research in the area of defining and describing LD is committed to understanding the specific difficulties children with LD present with. Much of this research is framed within the medical model, which has as its foundation positivism and empiricism. This results in research which is deficit-focused, in other words the focus is on pathology (Bailey, 1998:49). The second, or reductionist model fragments the phenomenon of learning disability into discrete units, each of which is researched. According to Gerber and Reiff (1991:1) the focus of the research towards the end of the 20th century was on "academic skills orientation," a clear reference to specific fragments or parts of the problem.

Research remains focused on the deficits, the things the child cannot do. Miles and Miles (cited in Riddick, 1996:5) focus on the deficits, including left / right confusion; b/d/ confusion; difficulty producing multi-syllabic words; difficulty rhyming; difficulty learning sequences such as days of the week, months of the year; difficulty recalling tables, digits: in other words the focus is on failure, weakness, insufficiency. Journals such as the *Journal of Learning Disability*, and *Journal of Special Education*, which by their names suggests that they are the definitive journals in the field, are filled with research articles that fragment LD by virtue of the research focus. Gresham, MacMillan and Bocian (1996) in their comparison of children with LD and mild cognitive impairment, identify *41 measures of*

ability and achievement, 41 ‘bits’ identified by standardized tests, which they use to then categorize children as LD as opposed to “low achievers” or “mildly mentally retarded.”

Even in the field of research, there are trends as to which particular “fragment” is the “in-thing” at the time. A perusal of research journals reveals that there are “fads” in research, and this is particularly apparent when journals dedicate specific volumes to particular areas of research. A review of the *Journal of Learning Disabilities*, for example, reveals a focus on definition at the end of the 20th century (Gordon et al., 1999, Jimenez Gonzalez & Hernandez Valle, 1999, Siegel, 1999, Stangvik, 1998, Stanovich, 1999). Just after a legal battle between students with LD and a large university there was a wealth of literature, including research articles, around the issue of defining LD and LD in college students and adults (Bashir et al., 2000, Madaus, 2008, Olfiesh & McAfee, 2000, Vogel et al., 2007, Westby, 2000). The current focus in research seems to be phonological awareness and its relevance to the development of reading (Anthony et al., 2007, Catts & Kamhi, 1999, Joly-Pottuz et al., 2008, Most et al., 2000, Vloedgraven & Verhoeven, 2007). Fragments of phonological awareness include skills such as phoneme recognition and production, segmentation at phoneme level (Most et al., 2000:100). Riddick (1996:12) highlights the apparent focus on the fragment of phonological processing and goes as far as to identify three areas of research within this small subcategory: research into phonological awareness, phonological memory and accessing phonological information in long-term memory. Researchers such as Most et al. (2000) even seek links between one discrete unit or fragment of the problem and another, as in their attempt to link phonological awareness and peer acceptance in children with learning disability. Other studies which fragment the phenomenon of LD include Badian’s (1996) investigation of phonological processing and lexical retrieval in children she labeled “dyslexic.” Whilst understanding the role of these skills in the development of literacy is no doubt important, there is

a danger that focusing on the minutiae does not improve our understanding of the phenomenon as a whole.

A body of recent research focuses on psychological aspects as opposed to the more academic aspects of LD. Kavale and Forness (1996) provide an overview and critique of the research into social skills of people with learning disability. More recent research includes Handwerk and Marshall's (1998) study looking at emotional problems and learning disability, the social persistence of children with LD (Settle & Milich, 1999), social competence of children with LD (Vallance & Wintre, 1997), interpersonal understanding in this group (Kravetz et al., 1999) and the self-esteem of people with learning disability (Humphrey, 2002)

The validity and reliability of some of this research is questionable. Kravetz et al. (1999) used semi-structured interview rather than closed questions in their research into interpersonal understanding in children with LD. However one of the tools they used, a story, was not appropriate for use with children with LD and their typically poor auditory memory (Ratner & Harris, 1994) due to its length. Children's responses may therefore have been related to their poor recall of the story rather than indicative of poor interpersonal skills. In addition to this the linguistic complexity and length of some of the questions asked may not have been appropriate for children with LD.¹² Handwerk and Marshall (1998), also focusing on the deficits of the child, looked at social competence or the lack thereof, in children with LD and children with severe emotional disturbance (SED). However the definition of LD expressly excludes learning problems that are as a result of emotional disturbance, and the definition of SED states that this must "adversely affect educational performance" (Handwerk & Marshall, 1998:328). Thus inherent in this definition is the assumption of LD. Therefore findings that attempt to separate out the social competence of

¹² For example: fourth and fifth graders were asked the following question after being told a story:: " Suppose that John decided not to climb the tree. What, in your opinion, would the children and the girl who asked for help think about what he had done?" (Kravetz et al., 1999: 251)

learners with LD vs. learners with SED are flawed. Furthermore, teacher and parent rating scales were used. The discrepancy between these scales is explained by Handwerk and Marshall as the fact that teachers spent more time with the children than parents and that parents were perhaps more tolerant and less willing to label or find fault with the children. However I suggest that as the teachers all knew that the children had been diagnosed LD, they possibly *expected* deficits, and this perhaps influenced their rating. This is an issue raised by Vallance and Wintre (1997:106) in their critique of other LD research. It is significant that in a way Handwerk and Marshall trusted the teachers' rating more than the parents' rating, revealing their own bias. Furthermore, the child's behaviour at school, particularly if they are failing to cope academically, may be very different to their behaviour in other contexts. Yet Handwerk and Marshall are dismissive of the parents' rating. In addition to this the way they established the LD in their sample population was using a quantitative methodology. Their research, which purports to be quantitative and therefore by implication objective, uses highly subjective rating scales as a data collection instrument. The behaviours that were highlighted by the checklist are all context-sensitive e.g. withdrawn, aggressive, anxious/depressed. Using this methodology did not allow for any investigation into the "when and why" of the behaviour, or the fact that a child who may appear aggressive in one context, such as a quiet classroom, is not in another, such as playing in a rugby match. In addition to this checklists were used where emotional difficulties were 'suspected': this *a priori* assumption may have resulted in teachers looking for behaviours that would confirm their assumptions. Furthermore they did not use consistent criteria to establish LD in their sample, some learners had been diagnosed by a multidisciplinary team if the team: "deem[ed] that the student exhibit[ed] LD based on clinical experience and observation" (Handwerk & Marshall, 1998:330).

Kravetz, Faust, Lipshitz and Shalhav (1999) present a meta-analysis of research into interpersonal understanding of children with LD. However as all studies they reviewed are already only looking at LD, it goes without

saying that a link will be found to LD. This then perpetuates the deficit or problem focus. In other words it is inevitable that reports of the various behaviour problems of children with LD seem to indicate that related social and emotional inadequacies are core features of these problems. They suggest that these children, as part of the “constellation of LD” (Kavale & Forness, 1996), have difficulty not only with written and oral verbal communication but are also less able to “read” nonverbal signs such as facial expression and tone (Kravetz et al., 1999:249). In a small scale study looking at the use of politeness markers in children with LD and ADHD,¹³ I found that the children lacked the linguistic structures such as indirect, hearer oriented strategies to mitigate high risk requests. Behaviourally, they understood the need for politeness markers though and as their default strategy used “Please may I/ you...”, even when a greater degree of indirectness was required. This I interpreted as a clear indication of pragmalinguistic rather than sociopragmatic difficulty (Thomas, 1983). In other words this suggests a language rather than a behaviour problem is behind the child with LD’s apparent rudeness. Vallance and Wintre (1997) suggest too that difficulty understanding figurative language is what lies behind the child with LD’s poor social competence.

Kavale and Forness (1996) also provide an overview or meta-analysis of the research into social skills *deficits* of children with LD. They further fragment these into: self concept, interpersonal skills and peer relationships, social adjustment, social competence and communicative competence (Kavale & Forness, 1996:227). Their bias is quite apparent in their rejection of qualitative research such as narrative research as “lacking rigor” (Kavale & Forness, 1996:228). Yet what the narrative methodologies allow for is a full, comprehensive picture to emerge, not a fragmented one. Thus they found that social skills deficits are part of the problem with 3 out of every 4 children with LD, but are not able to suggest whether this is part of a neurologically based syndrome known as LD, or whether it comes as a

¹³ Unpublished research report submitted to the Department of Linguistics, University of Stellenbosch in partial fulfillment of the requirement for the degree M.A. (General Linguistics)

result of the LD or a precursor. The fact that it appears that one out of every four children with LD does not present with social skills deficits is not discussed or explored at all, and in fact cannot be explored further unless one uses a qualitative methodology. This exemplifies what for me is a major criticism of much of the research in the field, and that is that only a partial picture emerges when researchers focus on deficits, and more than that fragment these deficits – it is inevitable that findings from such research do little to enhance our understanding of the phenomenon of LD.

Accepting the identified specifics of the phenomenon, another body of literature focuses on ...

3.2. Managing LD (within the context of fragmentary understanding of LD)

An important question I ask is if we look at LD in a different way and learn something new, how will our management change? This is a question I attempt to answer with this research. However it is first necessary to look at how LD is managed given the current fragmentary understanding.

Much of the current research is discipline specific, with each group of researchers looking at strategies to manage component parts of the “problem.” There is little agreement regarding appropriate management of such learners, particularly educationally. Oliver’s view that: “professional interventions come to be seen as often adding to [the] problems rather than seeking to deal with them” (Oliver, 1996:10) may be somewhat cynical, but there is a clear lack of agreement in the literature as to the most appropriate management strategies for children with learning disability. The debate regarding inclusive vs. exclusive or “special” education rages (Beloin & Peterson, 2000, Silliman et al., 1999, Vaughn et al., 1996). Inclusive education has been a fairly recent focus. As this is now policy in South Africa (DOE, 2001), it is an important element of this research. I

briefly discuss this below but this is a debate I return to in the presentation and analysis of my data in Chapter Five.

The focus in management is on improving the basic skills to close the gap between achievement and “general ability” or “potential” (Westby, 2000:4), regardless of the controversy around establishing this potential. Within the deficit model or paradigm, management involves the “fixing” of what educators identify as specific deficits or problems (Ainscow, 1998:11) or “filling in the gap” in terms of skills and not on anything else. Gersten, Fuchs, Williams and Baker (2001) provide an overview of research in the area of teaching reading and spelling to children with LD. Catts and Kamhi (1999) provide a comprehensive look at isolated areas, particularly reading, and provide relevant management strategies. Vallance and Wintre (1997) suggest intervention strategies should focus on improving the child’s understanding or interpretation of figurative language as a way of improving social competence. Settle and Milich (1999: 210) focus on the behavioural rather than academic issue and suggest that intervention should “focus on emotional regulation” to help the child control or manage her frustration. Again the focus is on “fixing” and “changing” rather than on understanding.

It is concerning that here too standardized tests are used to establish areas requiring intervention. Olfiesh & McAfee (2000) also used a quantitative methodology in their investigation into the evaluation of older learners with LD by tertiary education institutions. They too failed to develop their findings because of the nature of the methodology. They found more than half the practitioners interviewed were unhappy about the use of standardized psycho-educational tests as a means of planning service delivery. The practitioners reported supplementing test results with “unstructured, informal assessments and interviews” which Olfiesh and McAfee call “notoriously unreliable.” The question that begs asking is if this is the case, why are practitioners using these approaches? Clearly the standardized tests are not “measuring up.” The nature of the interviews and

the reasons for doing them are just two of the issues that could have been explored if a qualitative methodology had been used.

Some recent research into the different management strategies for children with LD reflects a different understanding of the phenomenon. Levine (2002) for example describes children with LD as being “differently wired” and therefore requiring intervention or management aimed at helping them compensate for or even use this difference, rather than focusing on the fragmentary academic skills that need intervention such as drilling word attack to improve reading, or developing phonological awareness to improve spelling.

The medical management of learning disabilities, particularly where attention deficit disorder is identified as part of the problem, is another controversial issue thoroughly discussed in the literature (Connor, 2005, Diller, 1998, Johnston, 1991, Tankersley & Balan, 1999). There is still some debate over whether ADHD should be seen as a medical condition needing medical intervention. This is moot – whether the labels are applied or not, educators are likely to acknowledge that there is a group of children who just seem unable to stay focused as long as their peers, who just don’t seem to cope with change in routine as well as their peers, who seem more impulsive and easily distracted by the usual classroom noises of pencils dropping, chairs scraping and children chatting.

Barkley, who is described by Diller as: “arguably the leading theoretician about ADD” (Diller, 1998:12) recommends Ritalin as “the definitive treatment for ADD” and Copps (n.d.) calls it: “the standard of medical therapy for ADD against which all others are, or should be judged.” This view is reiterated by Sternberg and Grigorenko (2000:187):

An example of successful pharmacological intervention through the manipulation of neural transmitters is the treatment of some disorders within the attention deficit spectrum with Ritalin.

However this is an extremely controversial view, and the literature resounds with the voices of both the proponents and the detractors. Accardo and Blondis (2001) refer to “anti-medication hysteria.” Doherty, Frankenger, Fuhrer and Snider (2000) looked at learners’ subjective impression of the effect of medication on their classroom performance. Although nearly half of the subjects said they wanted to stop taking medication, the researchers did not ask why. They had their empirical “blinkers” on and set out to test a particular hypothesis in as objective a way as possible. As a result what they learned was, I believe, of little value, particularly to the learners concerned.

The focus seems to be on getting all the learners to perform within a narrowly defined range. Read (1943), quoted by Eisner (1990:102) suggests this is: “making children into what they are not” and in fact: “bringing all children to the same place would be a liability, not an asset in education.” This is in fact what *Education White Paper 6* purports to address (DOE, 2001). I discuss this in the following section.

3.2.1. Inclusive education:

In South Africa, inclusive education relates to the Bill of Rights which protects all children from discrimination, including, but not only, those with special needs. It commits us to creating access to and provision of a process of education which is appropriate to the needs of all children, whatever their origin, background or circumstances. (Donald et al., 1997: 20).

Whether support should be offered in an inclusive education classroom or whether children with LD are best served in a specialized education setting is still hotly contested. It is necessary at this point to raise the issue of inclusive education, particularly as it pertains to the South African education context. At the very least what I hope to do is present a critique of the current policy, with a view to influence both practice and policy (Rickard, 2004).

I mentioned *Education White Paper 6* (DOE, 2001) in Chapter One. I wish to provide a brief background to the development of *Education White Paper 6*. Prior to the advent of democracy in South Africa in 1994, and even for some time after this, learners with special educational needs tended to be placed in a separate “special education” stream. Special schools existed for learners with physical disability, cerebral palsy, blindness, hearing impairment, cognitive impairment and similar conditions. In addition to this education was segregated according to race, and therefore multiple education systems existed. In fact there were fourteen separate education departments with resources distributed disproportionately in favour of the “White” schools (Donald et al., 1997, Naicker, 1999). In terms of special education, remedial schools were scarce but did exist for White learners. Even after the advent of democracy and the rationalization of the education departments and integration in schools, remedial schools were still populated by White learners. My personal experience as a speech-language therapist in a remedial school between 1990 and 2000, particularly prior to 1994, was that when a Black learner was referred for placement I had to write lengthy reports to the provincial Department of Education¹⁴ to motivate for the placement. In so doing it was my assessment of the learner’s language and auditory perceptual skills that was vital. Justification had to be made for the placement by ascertaining that the learner was not failing to cope in mainstream because of a language *difference*, in other words because s/he was not being educated in his/her mother tongue, but rather because s/he had a “language learning *disability*.” The irony of this was that this confirmation was made based on the learner’s performance on English-medium tests standardized on British and American children.

However with the advent of democracy and the development of a rights-based constitution and a national ethos of embracing diversity, education policy began to shift towards a more inclusive system, one which would be

¹⁴ At the time, prior to 1994, this was the Natal Department of Education; new provincial demarcations and renaming the provinces had not yet occurred.

expected to “[meet] the needs of the child as ‘normally’ and inclusively as possible, rather than the child having to be separated or excluded to suit the needs of the system” (Donald et al., 1997: 20). In 2001 *Education White Paper 6* was published. This document outlines the South African National Department of Education’s plans for an inclusive education system. It outlines the proposals for developing “resource schools,” and “full-service schools” and acknowledges the changes necessary at multiple levels for inclusive education to succeed (DOE, 2001). Inclusive education, according to Green (2001:4), refers to a system that embraces “the right of learners with disabilities to belong and learn in mainstream education.” Mainstreaming, or keeping a learner with special educational needs in a mainstream classroom, requires the necessary resources to meet the child’s special needs (Donald et al., 1997). Until such resources are in place however, a policy cannot be implemented and remains a plan or vision rather than a reality. Currently the additional support that a learner with special educational needs requires is seldom offered in mainstream, and where such learners are being mainstreamed it is the parents who are bearing the financial burden of providing support by way of facilitators, teacher aides, technology such as FM systems,¹⁵ personal computers or laptops, to enable their children to cope in the mainstream environments. Many mainstream schools are not wheelchair accessible. Developing the requisite skills in teachers, adapting curricula, providing schools with the necessary resources, are just some of the needs identified in order to restructure schools to meet the learning needs of all learners (Green, 2001).

A further criticism of *Education White Paper 6* is that reference is also made to many changes that are not quantifiable: such as changing attitudes and behaviour (DOE, 2001:16). Of further concern is the comment that there are learners who should be mainstreamed due to the level of support that they require, such as “low-intensive support,” and “moderate support”

¹⁵ Personal amplification systems that amplify only what is directed into a microphone (usually worn by the teacher) and thus allows for amplification of the teacher’s voice without amplification of all the background classroom noise. It is used both with children with hearing impairment who wear hearing aids, and for children who have normal peripheral hearing but who present with auditory processing disorder.

(DOE, 2001:21). Such comment is concerning for a number of reasons – the need for and level of support required is often difficult to measure, judgments made about who requires “less” or “more” support are at best subjective, and nowhere is there reference to consulting with the learners themselves about their needs. The reference in *Education White Paper 6* to “transitory learning difficulties” (2001:10) is equally vague as no further explanation of what is referred to here is provided. What *Education White Paper 6* does differentiate is those learners who have “barriers to learning and development that are rooted in organic or medical causes” (2001:12). From the above lengthy discussion about defining LD, it can be seen that there is growing consensus that it does indeed have an organic or neurological basis, and in fact Bigler et al., (1998) refer to the legitimacy the field gains by being ‘medicalized’. My question then is: does one have to subscribe to this understanding of LD in order to access the level of support reserved for learners with “barriers to learning and development that are rooted in organic or medical causes?” If so, are we not then in danger of being obliged to perpetuate the “pathology” model of understanding of LD?

In Chapter Five I present evidence to suggest that in fact inclusive education is not necessarily in the best interest of the learner. Research that has focused on learners’ experience of specialized versus mainstream education is not all that supportive of inclusion. Rogan and Hartman (1976, cited in Gerber & Reiff, 1991) found the “specialized schooling” was most beneficial for their participants with LD; Humphrey (2002) found that children with learning disability, which he terms dyslexia, in a mainstream environment had a lower self esteem, and more negative self concept than those who were not “dyslexic.” Teasing and bullying were also more likely to occur with these children in the mainstream. It is here, in this environment, that their differences and difficulties are most noted. Bear et al. (1998:92) raise the issue of social comparison, or the comparison of oneself to peers or others in the class:

An important implication of the social comparison process is that the self-perceptions of children with LD are likely to suffer when the children are integrated into general classrooms as a result of comparing themselves to higher achieving peers.

In addition to this, instruction aligned to the students' ability and achievement levels is also likely to influence their self-perception (Bear et al., 1998). I believe that this instruction can best be given in a specialized environment, and by a teacher who has the necessary training and insight to adapt her instruction to the level and needs of the child. This raises questions about whether inclusive education really is in the best interests of the learners with special educational needs, questions I return to in Chapter Five.

Guterman (1995) looked at how satisfied children with learning disability were with the services provided to them and found that although the learners interviewed did not feel the special services they received were particularly beneficial, they did express a preference for specialized rather than mainstream services. This flies in the face of arguments for inclusive education, and is supported by my data, which are discussed in detail below in Chapter Five. Norwich and Kelly (2004) present findings that at first glance seem to support mainstreaming for learners with special education needs. Although they interview children with "learning disability," this is LD as defined in the UK, in other words their sample population included learners with mild to moderate cognitive impairment, including communication problems. Those learners in special education who were interviewed were more cognitively impaired than the mainstreamed interviewees, or had multiple disabilities. Norwich and Kelly (2004) present results that suggest one in six learners in special education had positive views about mainstream and one in three had negative views. This does not, in my opinion, support their conclusion that learners in special education show a clear preference for mainstream. Another concern about the results and one that I raise in Chapter Three about my own data, is whether the participants presented their "real selves" or whether their

responses were influenced by wanting to please the researcher. This criticism can also be applied to Guterman's (1995) research, described above.

3.3. Experiencing LD

It is an objective of this research to explore the child's understanding of his/her LD. In so doing I hope to illuminate the mismatch between the label "LD", which I believe confines the outsider's understanding by virtue of the boundaries implied by a definition, and the child's experience. I hope to shed light on the tension between the structures (definitions) and agency (experience) (Thursby, n.d.).

The question I ask is what are the experiences of children with LD? There is minimal research in the field of LD that focuses on the experiences of the learner with LD. However there is a small, but growing body of research, largely ethnographic, that is beginning to move in this direction as it shifts away from focusing on the child's deficits and looks at his/her experiences and those of the family, and the impact of the LD on the family (Dyson, 1996, Gerber & Reiff, 1991, Heaton, 1996, Ingesson, 2007, Neuville, 1995, Thiessen, 1987). It is interesting that the motivation for researching the experiences of learners with LD is largely personal, with researchers such as Augur (1995), Heaton (1996), Kurnoff (2000), Neuville (1995) and Riddick (1996) coming to the research as parents of children with LD and Frank (2002) as part of a small group who write their own experience of LD. Frank (2002) stresses the importance of understanding the child's experiences of LD as each child's experiences are different. In writing about the experiences of children with LD then, in particular individual experiences, a broader picture begins to emerge. In researching experience, which is described by Bruner (1986:50) as "the primary reality," we can move towards a more detailed and context-specific understanding of LD. Kurnoff (2000) presents the experiences of over 100 people across the age range with what she identifies as "dyslexia." Although she writes a

book specifically aimed at parents, she presents themes or common experiences in a way that provides a strong foundation for my own research. These include dealing with the initial diagnosis, school placement, experiences of siblings and the various phases of schooling.

Auto-ethnographies are becoming popular in the field of LD as well as in others fields. Neuville (1995) for example writes as a mother of three children with LD, and she describes the experiences of her sons and the family. However she privileges the adult's voice, not the child's. Furthermore no attempt is made to go beyond the description of the experiences and theorize about LD. Research to date that purports to describe the experiences of children with specific learning disability leaves little room for the child's voice – views and feelings are often assumed by the researcher and / or educators involved in the research. Riddick (1996) looks at the perceptions of both children with learning disability and their mothers. However the questionnaire she uses is very specific and many closed (yes/no) questions are asked. She privileges the mother's view, for example when a child expresses that she did not feel as though she had a problem in a certain area and the mother disagrees, Riddick comments on the child's "defensiveness" rather than exploring whether the child's perceptions were more reliable than the mother's. Another criticism of this research is that the questions in the questionnaire leave little room to explore the things the child felt good about or the areas where the child was achieving. Edwards (1994), in her study of the emotional reactions to dyslexia, focuses on educational experiences and scholastic difficulty. She also uses many closed (yes/no) questions in her questionnaire which do not allow for the generation and exploration of areas the researcher may not have considered. Using this form of questioning therefore limits the data generated.

Thiessen (1987) first looked at how learners with LD experience the curriculum some 20 years ago. In his study he did not limit his data by using questionnaires or even semi-structured interviews but used a

conversational approach with his participants. He therefore is able to provide a broad and deeply personal view of the curriculum experiences of his participants. However he, like Gerber and Reiff (1991), interviewed young adults who were no longer in the school system at the time of the interviews. Whilst this enabled them to reflect over their school history, they were interpreting their experiences with the benefit of hindsight and the maturity of adults. It does not allow for us to understand how they experienced their LD *at the time*.

3.4. An LD identity?

Behind my critical questions and pervading my discussion is the hidden question: is there an “LD identity?” As I identify themes in the data I will reflect on the learner’s changing self –identity. I argue for the shifting, dynamic nature of identity (Ryan & Deci, 2003). There is a small body of literature that examines the notion of “an LD identity,” but this is predominantly using the term ‘learning disabilities’ to refer to intellectual impairment, as discussed above in section 3.1 It therefore refers to an entirely different group and thus has no relevance here.

Chanfrault-Duchet (2004: 268) describes identity as: “a construction that articulates different components of the self.” Eakin (1999) cites Neisser’s five selves – of these my interest is in the three reflexive selves (Eakin, 1999:24), particularly the extended self and the private self. The extended self is described as “the self of specific experiences...and specific and familiar routines” (Neisser, 1988:36 cited in Eakin, 1999:23); it is the self beyond the here and now, the “self of memory and anticipation – the self in time” and, significant for my purposes because it is the self that is typically revealed in autobiography (Eakin, 1999:102). The private self on the other hand is described as “the only person who can feel this unique and particular pain,” in other words the nature of each experience is unique to the private self (Eakin, 1999:23 citing Neisser, 1988:36). This is also important for this study in that I wish to illuminate the experience of LD for

each of my informants, and in so doing explore their own “unique and particular pain.”

In attempting to answer the critical question – how do learners with LD experience their LD, I look at how their identity is or is not moulded around the ‘wearing’ of this label, in other words how the ‘wearing’ or ‘owning’ of this label impacts on the identity and self concept of the ‘wearers.’ I look at “the sufferers experience” of LD (Rickard, 2004). For my purposes then it is important to highlight how the structures, such as formal definitions, diagnostic categories, and school systems that are themselves defined, impact on the identity formation of my informants. Stets and Burke (2003) refer to hidden structures too, those that are not obvious such as gate-keeping at schools and exclusion of certain groups. This could include children who are excluded by virtue of high school fees, distance from school or lack of transport, even IQ scores.

I take the social interactionist view that identity is a social construction, in other words it develops in a social context (Harter, 2003). Our sense of self, or our self –identify, is shaped by society, particularly the social groups to which we belong (Devos & Banaji, 2003). Identity changes across the lifespan (Ryan & Deci, 2003). We therefore have multiple selves and present these depending on the group or context we are in. Usually we describe ourselves first by that which differentiates us from the group, that which distinguishes us from the majority. School is possibly one of the most significant social contexts or groups to which children belong, the context of school plays a significant role in the development of self-identity. If this is indeed the case, one could posit that the identity of a child with LD should then be shaped during his school years to a large extent by the social milieu of the school and classroom. As the child with LD spends most of the day in a group where s/he performs differently, is judged to be different, can one expect him/her to reflect that “difference” or “deficit” in their identity?

The social interactionists' notion of the looking glass self is particularly relevant. According to this theory, we see ourselves as we think others see us, particularly those we consider significant and whom we trust. Harter (Harter, 2003:268) asks: "Mirror, mirror on the wall, whose opinion is the most critical of all?" For school learners this includes parents, classmates and teachers. Harter goes on to say:

Significant others constitute the social mirror into which the child gazes in order to detect his or her opinions toward the self. These perceived opinions, in turn, are incorporated into the evaluations of one's worth as a person. (Harter, 2003:628)

For me it is particularly significant because it is this feedback – especially from significant others such as peers and parents, that impacts on the way individuals think about themselves. For a child with LD and the low self esteem so typical of LD (Frank, 2002, Humphrey, 2002) this is particularly so. The implication here is that the child who thinks significant others see her as disabled, less than or 'in deficit' in some way is likely to see herself thus. The corollary of this is that if the child feels adequate in important areas, if s/he receives support from parents and peers in what s/he considers a "domain of importance," this has a positive effect on self-worth (Harter, :628). Bjarnason (2000) found that how parents and peers viewed the adolescent with a disability, as well as their school experiences, had more of an impact on how they viewed themselves, and therefore their self – awareness and identity than the extent of the disability.

It is social comparison, in other words that which distinguishes or differentiates a child from the majority, that in particular influences the self concept of the child with LD, as s/he is frequently compared by others as well as him/herself to achievers in the classroom context. In other words, for learners with learning disability, in the classroom it is the failure that makes them different. In a remedial environment classmates see the learner with LD like them; in a mainstream environment the classmates see the child as different: weak; even 'stupid.' In the particular remedial

environments I have either worked in or visited, learners are constantly told by teachers, and in some cases parents, how lucky they are to have been chosen to attend the school. They are reassured that they have been ‘selected’ because they can achieve. This then feeds into a positive self esteem. What makes them different to their classmates or peers in this context may be their creativity, their hair, eye or skin colour, their athletic prowess and such. Learning difficulties and failure are no longer the things that set them apart or make them different to the group.

Self knowledge is acquired not only through social comparisons but also by “performance feedback” (Kernis & Goldman, 2003) This is particularly relevant for the discussion that follows where I show how these factors have impacted on my informants’ self-knowledge. Actions, especially most recent actions, also influence self appraisal (the way the child thinks about himself) (Kernis & Goldman, 2003). In the case of the child with LD, if the immediate experience is of success, praise and positive feedback, this can then impact on the way we he views his LD. Thus opportunities for success and for achievement in other spheres become important, to counterbalance the classroom failure. I am therefore interested in how the opportunity to experience success changes their self identity, if at all.

4. Conclusion

In this chapter I have presented an overview of the dominant thinking about LD. I am critical of the notion that in order to understand LD we need to break it down into microscopic ‘bits.’ It is apparent then that not only does the existing body of research in the field of LD ignore the child’s assets or strengths, a holistic view of the child is not taken. A review of methodological approaches reveals that the favoured methodologies perpetuate the reductionist, deficit focus. Furthermore research that purports to take the child’s view into consideration does not really do this. I believe the only way to address the gaps and silences in the literature is to use an alternative methodology. The rationale for this is discussed in the

following chapter. I conclude this chapter by presenting an analytical framework which I see as an alternative way of understanding LD. I propose that a different picture may emerge if we focus on how the child with LD interprets his/her condition. I believe we can see this if we explore the child's experiences of LD and how these experiences impact on the construction of his/her identity. In the following chapter I present and justify the methodology used in an attempt to illuminate these experiences.

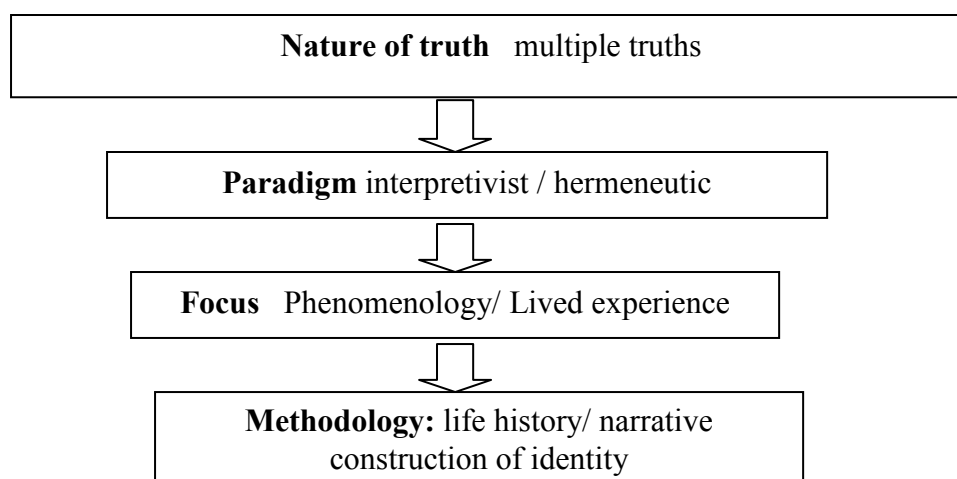
CHAPTER THREE

METHODOLOGY AND ANALYTICAL FRAMEWORK: pushing the button

In this chapter I elaborate on the methodology and research design covered superficially in Chapter One. My responsibility as a researcher is to attempt to “validate [my] informed guesses.”¹⁶ The purpose of this chapter therefore is not only to position the research but also to position the researcher (Henning, 2004:26), and I attempt to clarify my own positioning. The rationale for choosing a qualitative, life history design is described. The research process, through all three stages or phases, is described and the chapter closes as a framework for data analysis is outlined. This is developed further in the following chapters where data are presented and I begin the process of analyzing and interpreting.

1. Introduction

By making choices about LDs ontology and epistemology I present one specific way of understanding the phenomenon of LD. These choices, described in Chapter One, are illustrated in the flow chart below:



¹⁶ http://www.ai.mit.edu/people/jcme/papers/1986-ai-memo-871/ subsection3_6_1.html)

The focus of this study is the lived experiences of children with learning disability. The rationale for the present study arose partly out of a dissatisfaction with the themes or the theories being generated by research that is reductionist and deficit-focused. I have described much research that is framed within the medical, logical-empiricist model in the preceding chapter. I have illustrated how this results in research which is deficit-focused, in other words the focus is on pathology (Bailey, 1998:49). Furthermore the fact that this phenomenon of learning disability is researched in fairly distinct and semi-autonomous fields, with little interdisciplinary and cross-disciplinary research, results in reductionism, where fragments of the problem are researched. I aim, through this research, to develop a new, broader understanding of LD and thus hope to reinterpret the experience of LD in a new, more positive way as Oliver suggests when he says: "...with the developing of a politics of personal identity, the experience of disability is being reinterpreted in positive rather than negative terms" (Oliver, 1996:131).

Identity is fluid and ever-changing and we adopt different identities in order to belong to specific groups (Ryan & Deci, 2003:10). By exploring more fully what it means to "have" or to "be LD" I am interested to see whether an "LD identity" is acquired, and if it is, how it is conceptualized and present in a narrative of self-identity. Ricoeur (1991:28) suggests that it is only in narrating our lives that we give them meaning when he states: "a life is no more than a biological phenomenon as long as it has not been interpreted." A life story can be seen as a narrativisation of that period between life and death. In fact Eakin (1999:113) talks about "a lifelong trajectory of self narration." I propose that a new way of understanding LD may develop from an exploration of this very interpretation, in other words the way the individual interprets her experience of LD. It should thus be apparent that my chosen methodology serves both as a methodological strategy and an analytical framework as I look at how my informants transform their experience into a cohesive narrative of identity.

2. Rationale for a qualitative design, life history methodology

There is a long history of using biography in educational research which Connelly and Clandinin justify thus:

Narrative and life go together, so the principal attraction of narrative as a method is its capacity to render life experience, both personal and social, in relevant, meaningful ways (Connelly & Clandinin, 1990:10).

However, much of the current narrative research in education is centred on the educator, or teacher. I shift my focus to the experience of the learner, and in particular the learner with special educational needs. I come to this with a background in the health sciences rather than in education. However even in health studies there is a developing trend to research the experiences of the client (Rickard, 2004).

The value of using life histories in research in social and human sciences is well documented (Atkinson, 1999, Cole & Knowles, 2001, Connelly & Clandinin, 1990, Josselson & Lieblich, 1993, Kathard, 2003, Plummer, 2001), and allows for the crossing of discipline boundaries so lacking in research in the field of LD. I do not believe existing research, even research that focuses on experiencing LD, allows for the development of insight into how the child with LD interprets or understands his/her condition. By using a life history methodology and moving away from empiricism, positivism, reductionism and the deficit-based views perpetuated by existing research, throwing light on how the child with LD experiences his/her condition may allow for a new understanding of how s/he interprets her condition.

My ultimate goal is to inform practice. Rickard (2004:171) highlights the palliative nature of narratives ; talking about the problem can be healing in itself. Apitzsch et al. (2004) describe the “dual reward” gained from using biographical approaches to research (such as a life history approach):

On the one hand they offer opportunities for more individualized and therefore more sensitive and appropriate outcomes and knowledge gained from fully expressed user identities and, on the other, the possibility of more empathic and enabling practice once professionals and practitioners accept that they can learn from the stories they hear (Apitzsch et al., 2004:6).

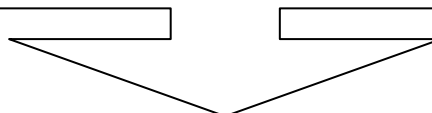
It is my hope that the stories generated by this research teach us about LD, and that in fact they reveal aspects of this particular “condition” that are not revealed by other methodological approaches. This may then present alternate ways of intervening and thus change our practice.

3. Research process

Three phases were envisaged for this study, a preparation phase, a data collection phase and a data analysis phase, summarized in the flow chart below:

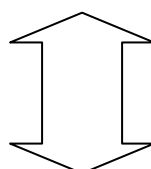
PHASE ONE: PREPARATION PHASE/ SAMPLING

- Selection of sites and informants
- Gaining access
- Informed consent



PHASE TWO: DATA COLLECTION

- Data sources: 3 data sets
Children with LD
Documents and artifacts
Researcher
- Data collection instruments and methods:
Interview schedules
Document analysis schedules



PHASE THREE : DATA ANALYSIS

- Data analysis strategies-*qualitative*
- Data analysis processes-*thematic categorization*
- Data analysis techniques-*factoring, clustering, weighting*
- Data interpretation
- Data representation-*narrative forms*

Figure 4: Flowchart to show research process

3.1.Phase 1: Preparation phase

3.1.1. Selection of sites

Before choosing participants for this study I selected research sites that allowed me access to the potential informants. I initially identified three research sites which were selected due to my existing relationship with the management and pupils at the schools and due to their proximity (convenience). Bruyn, cited in Harry (1996:295), suggests that the proximity of the researcher to the informants and the opportunities for interaction between them serve as “indexes of subjective adequacy” that strengthen qualitative research. Furthermore admission criteria to two of these sites, a remedial school and a remedial unit in a mainstream school, stipulate that the diagnosis of LD¹⁷ and not emotional disorder, language difference or delay or cultural difference or deprivation must be the primary reason for scholastic failure. The mainstream site was selected as it allowed for the illumination of children’s experiences of LD outside a remedial facility with its assumed additional support. It also allowed for the illumination of experiences of children with LD in a context where peers do not have learning disabilities.

I presented an abridged version of the research proposal to principals at each site and at this point permission was not granted by the principal of the remedial unit. This resulted in the final selection of the two research sites, which were:

- A well resourced, urban remedial school in a middle income area
- A well resourced mainstream school which has a support unit but children remain in mainstream classrooms

Both research sites draw learners from a wide geographical area, from mixed socio-economic groups and from diverse cultural and linguistic backgrounds. The medium of instruction in both the schools is English, so

¹⁷ The difficulty in making this diagnosis and the merits or otherwise of using standardized assessment procedures such as IQ tests has been thoroughly explored in the second chapter of this research report.

those learners who speak other languages at home are assumed to have adequate English language competence to cope with this as their language for learning

3.1.2. Sampling

Purposive sampling was used in order to select informants who would “best answer the research questions” (Creswell, 1994:148), in other words informants meeting certain specific criteria were “hand-picked” (Goodson & Sykes, 2001). Sampling involved both **convenience sampling**, where informants were selected because of access, and **self selection**. However I tried to keep some homogeneity in so far as all informants had to have had a history of learning difficulty and remedial intervention. Due to the changing labels, attitudes and educational policies and practices with regard to the learning disabled child, it was necessary to select informants who were currently in the school system.

I presented the proposed research plan to staff at the two research sites in order to identify potential participants. School staff, that is the teachers and psychologist, then suggested names of learners who met the criteria and parents were contacted directly. I presented a copy of the abridged research proposal to parents and discussed the proposed research with both a parent and the potential informant. Once I had identified potential informants through this process of purposive sampling, all were thoroughly advised regarding the purpose and nature of the research and assured of anonymity and confidentiality. The ultimate number of informants was decided once presentation to parents and learners had been done and a pool of potential participants identified. The final selection criteria included:

- Confirmed diagnosis of “learning disability” by both educators and psychologist
- Ability to express themselves well – either verbally or in writing (this is discussed below)
- Diversity in the group –mixed genders, cultural diversity.

Participants were not chosen for their representativeness but so that “uniqueness of each case” could be acknowledged (Scott, 1997:158).

The participants or **informants** (Cole & Knowles, 2001, Kazmierska, 2004) who were selected were children, over 11 years of age but under 18. There were two primary reasons this age group was selected. Badian (1996) states that a definitive diagnosis of dyslexia (the term she uses), can only be made after the age of 10. Furthermore due to the nature of the study and the need for the informants to articulate their experiences (Bargdill, 2000), younger children were not included. Eakin (1999, citing Wolf) identifies the age of emergence of the “authorial self” as between 2 and 4 years of age. For each of my informants their stories start in the preschool years (age 4-5). The age of my informants at interview was important as they were old enough to understand what Polkinghorne (1988) calls narrative ordering, and have developed the ability to “organize autobiographical memories in [a] temporal framework” (Eakin, 1999:113).

One of the informants was my own child, a 14 year old female (at the outset of the study) who has a history of LD. Five other informants were selected, with 4 from the mainstream site, three of whom had spent at least two years in a remedial school previously. All of these mainstream informants were in the junior high school phase, and were 14-15 years of age at the initial interview, in grades 9 and 10. Apart from my own daughter, there were two other females and one male. A further two informants were in a remedial school in the senior primary phase, both males aged 13 and in grade 7. During the course of the study one of these went into high school in a mainstream school. After the first interview, the other one dropped out of the study. All informants who expressed a willingness to participate were selected. I did not attempt to increase this number when one dropped out as I felt the nature of the research did not require a large sample. The relevant biographical details of each of the informants who finally participated in this research are summarized in the table below:

Informant	M.	H.	B.	S.	A.
Gender	F	F	M	F	M
Age at identification or diagnosis of LD	6 yrs	6 yrs	8 yrs	9 yrs	8 yrs
Age through data collection process (from initial interview to final interview)	14-16	14-16	13-14	14-15	13-14
Grade at initial interview	gr.10	gr. 10	gr. 7	gr. 10	gr. 9
Grades in remedial school/unit	gr. 2 -3	gr. 2-3 and latter half of gr. 1	gr. 6-7	nil	gr. 3-4 and repeat of gr. 4

Table 1: Profile of informants who participated throughout the process

Plummer (2001) suggests rather than an ideal number of participants the time spent interviewing was important: he suggests 6-10 hours of interview data may be sufficient. Carrier (1987) in a similar study with young adults with LD interviewed two participants but does not indicate how many hours of interview data he collected from each. Gerber and Reiff (1991) interviewed nine adults with LD and collected three hours of interview data from each. Meier (1998) used a similar methodology, albeit to answer a different question, and interviewed 23 participants but only had one interview lasting between one and two and a half hours with each. Norwich and Kelly (2004) interviewed learners with what they refer to as “learning disability” but they use this term as used in the United Kingdom, thus their sample included learners who had mild to moderate cognitive impairment. They interviewed their participants for 45-60 minutes each, on average.

Unfortunately the final research group only included White, English-speaking males and females. Two important issues must be raised at this point. The first is the apparent limitation of not having a racially diverse sample group, particularly in a country with such racial diversity as South Africa. However this is partly as a consequence of the difficulty confirming a diagnosis of LD in a child who is not being educated or assessed in her

mother-tongue. The absence of widely recognized and appropriately normed standardized tests for bilingual or multilingual learners in South Africa at the time meant that many of the learners in remedial units and schools who were not English mother-tongue speakers may well have been there as a result of their language for learning not being their dominant language or mother-tongue. This may then have impacted on scholastic performance to the point that the learner presents as LD, but this is not due to some intrinsic processing deficit as implied by the DSM –IV and NJCLD definitions of LD.

The second key issue may be related to different cultural views about the fairly invasive nature of the research (interviewing in their homes, asking for recorded journals) and even parents' trust in me as researcher. South Africa's long history of injustice and oppression, and the concomitant racial tension, may have resulted in barriers to establishing trust relationships across races. In other words my race may have been an issue. As a White South African I may have been perceived as untrustworthy or likely to abuse or misuse my 'power' as researcher. There were initially three potential participants from the Indian and African race groups identified during the process of purposive sampling. However parental consent was not given for the children to participate in the research. The critical ethical issue of informed consent is discussed below.

3.2 .Phase two: Data collection

3.2.1.Data collection process

Fontana and Frey (2003:99) state:

Human beings are complex, and their lives are ever changing; the more methods we use to study them, the better our chances to gain some understanding of how they construct their lives and the stories they tell us about them.

In this study therefore I used a multi-method approach to data collection. Data were collected from a number of sources, including audio journals kept by participants, “guided conversations” typical of life history research and visual representations such as collages or life maps submitted by the participants. The table below summarizes the data collections process.

Rationale for data collection	To illuminate the lived experiences of children with learning disability
Data collection methods	Semi-structured interview artifact related interview document analysis
Data sources (expanded below in Table 3)	Children with LD: Semi-structured interview Audio diary Researcher’s reflective journal Documents: school files, reports, education policy documents Artifacts: collage, paintings
Sites for data collection	School Home Cafe

Table 2: Overview of data collection process

Using multiple data sources and multiple collection methods allows for validation or “crystallization” of data (Richardson cited in Ely et al., 1997:35, Guba & Lincoln, 1998) and to develop rich narratives (Connelly & Clandinin, 1990). Sources , which included interviews, journals and collages and pictures, are indicated below in *data sets*. For ease of reference data sources, data collection instruments and methods will be discussed in sets in the detail that follows table 2. There were three data sets, and multiple data sources, as depicted below:

SOURCES	Semi-structured interview: individual	Semi-structured interview: artifact related	Audio diary: informant	Reflective journal: researcher	Document analysis
DATA SET 1 Child	*	*	*		
DATA SET 2 documents		*			*
DATA SET 3 Researcher				*	

Table 3:Overview of data sets and data sources

3.2.1.1. Data set 1: Primary voices

The **data sources** included audio diaries or journals, unstructured interviews as well as artifacts, such as school reports, paintings by informants and collages constructed during the data collection phase. The usefulness of diaries is well documented in the literature (Cole & Knowles, 2001, Goodson & Sykes, 2001, Plummer, 2001). **Audio diaries/ journals** were used as reflective journals, where the child recorded his/her experiences on a random basis. This method was selected rather than a written journal due to the negative feelings and difficulty children with learning disabilities may have with written language.

Each informant was provided with the necessary resources to keep an audio journal. S/he was encouraged to record initially by a reminder telephone call from the researcher and a reward system (tangible reward such as sweets or movie tickets) for recorded entries. Attempts to get regular entries were abandoned as I did not want to compromise the purpose of the journal. It was important that it serve as an outlet, or an opportunity to discuss something at any point, rather than become a chore. The informants were made aware of the fact that all recorded information may be used as data for the study. They were however assured of anonymity and confidentiality.

Artifacts (Cole & Knowles, 2001) such as photographs, school books and artwork selected by the informants were included as data sources, where these were introduced by the informants during interviews or requested by me to support or supplement comments made in audio journals. Each informant was asked to provide a “life-map” (Gray & Ridden, 1999) or a collage depicting the way they see their school experiences as a supplementary form of data. Alerby (2003) stresses the importance of using more than just verbal or written forms of expression, particularly in a study about experiences. I found this resulted in some powerful data. What did not emerge or was even denied in the interviews, emerged in the collages, audio journals and miscellaneous written submissions such as a short essay submitted by informant H. after her second interview, and a written journal submitted by informant M.

Data collection instruments were developed and refined during phase one. Scott (1997:157) suggests that using interviews, document analysis and observation enables the researcher to “construct events through the eyes of key informants” which is what I set out to do. As the researcher I was the primary instrument in that I guided and influenced different aspects of the research (Cole & Knowles, 2001:10, Creswell, 1994:145, Harry, 1996:292). Denzin and Lincoln (2003:48) stress that the interview “is not a neutral tool, for at least two people create the reality of the interview situation.” I am aware that I too contributed to the dialogue, and was not merely a neutral observer (Meier, 1998).

Strategies included **unstructured interviews or guided conversations** conducted with informants to elicit biographies. Occasional prompts or “pointers” were necessary to focus the interview (Scott, 1997:165). In other words interviews were conversations, or what Salter (1998) describes as “interviews as chat,” bound only by time and context (Cole & Knowles, 2001, Goodson & Sykes, 2001). The informants and I therefore produced what Bargdill (2000:193) refers to as “individual situated narratives.” This was an inductive research process, where issues arising out of the data shaped future interviews (Creswell, 1994, Guterman, 1995, Meier, 1998). The interviews were organized according to Oplatka’s (2001) stages, that is an opening stage, a discussion stage, which focused on school experiences, and then developed into more detailed conversations elaborating on specific experiences. An interview schedule was prepared in order to provide prompts to guide the conversation.¹⁸

The importance of an appropriate entry to the interview and the need to develop a trusting and nurturing relationship between the researcher and informant is stressed by Connelly and Clandinin (1990). I set up each initial interview by giving my own brief biography and revealed my own interest in their stories. As most of my informants were pre-adolescents during the data collection /interview period, I found that the narration of their “life

¹⁸ See appendix 11

with LD” stories was not as flowing and without interruption as suggested by Kazmierska (2004). However I attempted to keep the probes broad, such as “tell me more” and “let’s chat about that a bit more,” particularly where a specific event or experience was described. My feeling was that if this was something the informant had chosen to include in the telling of their story, even to exemplify a feeling, then the incident could be viewed as a “pinpoint” in the narrative. I listened to my informants first and gave them “the time and space to tell their stories” (Connelly & Clandinin, 1990:4). However by virtue of being a listener I became a co-author of the stories (Kazmierska, 2004, Meier, 1998). My nonverbal responses to their stories, agreement, interjections and even questioning for them to elaborate on or clarify points would all have shaped the narratives to some extent.

A “feminist interviewing ethic” was used which Denzin and Lincoln (2003:48) describe as requiring:

... openness, emotional engagement, and the development of a potentially long-term, trusting relationship between the interviewer and the subject....[as well as transforming] interviewer and respondent into co-equals who are carrying on a conversation about mutually relevant, often biographically critical issues.

I therefore attempted to present myself as a caring co-equal with the informants, with equal power between us. Graaff, Reed and Shay (2004:63) describe the qualities of a researcher thus: “researchers must be resilient, patient, persistent, meticulous, passionate, personally involved.” My own personal characteristics of compassion and empathy, and my training in a so-called “helping profession” were an asset in this process. In fact Denzin and Lincoln stress the benefit of such a background:

... the clinically oriented qualitative researcher can... create spaces for those who are the studied (the other) to speak. The evaluator becomes the conduit through which such voices can be heard (Denzin & Lincoln, 2003:38).

There was however a conflict within me at times as I tried to tread the fine line that separated me as therapist and me as researcher. Meier (1998) mentions the tension he experienced being a researcher/ interviewer and his training as a therapist, that resulted in him wanting to help and provide support or intervene rather than just interview participants. I felt this too, especially with A. who had such difficulty expressing himself due to his word finding difficulty and his dysfluency. The speech-language clinician-Me had to listen quietly while he struggled, and not give in to the temptation to provide phonemic and semantic cues to help with word retrieval, or to suggest fluency techniques when his fluency broke down. This tension was also evident when M. reported an incident of cheating in a school test and the interviewer-Me just wanted to capture this data; the therapist-Me wanted to reassure her that all would be alright and it was understandable that she felt so pressurised, and the mother-Me wanted to reprimand her for her dishonesty!

There were two types of interviews due to my differing relationships with the informants. Certainly the interviews with my daughter, with whom I have a “primary relationship” (Bailey, 1987) can be described as “phenomenal interviews” (Massarik, 1981) in that there were often no clear boundaries to the interviews – they were ongoing, because of our access to each other. In addition to this there were times when her behaviour was used either as a cue to an interview or where I could ask her to record an entry in her audio journal. I was more privy to her day to day experiences and therefore was able to ask questions and “collect data” at unexpected times. In addition to this the trust between myself as interviewer and M. as interviewee, particularly the trust that I would tell her story, was apparent when she recounted an incident where she cheated on a test at school. This is discussed in detail in Chapter Four but I mention it here as evidence of the “maximal mutuality of trust” described by Massarik (1981) as typical of this type in interview.

The interviews with the other informants could be described as “depth interviews” as here:

the interviewer is genuinely concerned with the interviewee as a person, going beyond search for delimited information input. In turn... the interviewee sufficiently reciprocates this feeling, valuing the interviewer's motives and seeking to respond in appropriate depth (Massarik, 1981:203)

With these informants I have what Bailey (1987) refers to as a "secondary relationship," one which had a specific purpose and that was to elicit data for this research.

There were at least three interviews with each of the informants over an 18 month period, the first two covering a specific scholastic phase and the third focusing directly on the LD. The extended period was selected to allow for the development of a relationship between the researcher and the informants. The time spent interviewing each participant varied, as three submitted more detailed audio and/ or written journals and even collages. However on average I had 5-6 hours of recorded data (including interviews and audio journals) per participant, ranging from 5 hours for the most reticent informant (2 interviews and 3 audio journal entries) to over 10 hours (3 interviews, 6 audio journal entries) plus visual representations/ pictures from the most garrulous informant! For one informant scheduling of the third interview became difficult and when it was cancelled after being re-scheduled three times, I decided that for this participant this seemed to mark the end of the data collection process and further interviews were not pursued. Data collection from the informant who was my daughter is difficult to quantify, as although she was also interviewed and kept both an audio and written journal for a time, interviewing often happened on an ad hoc basis.

The data were collected in different contexts, as the setting in which communication takes place dictates to some extent the nature and type of information that may be forthcoming (Cole & Knowles, 2001, Kazmierska, 2004, Van der Gaag & Dormandy, 1993). Interviews therefore took place at the informant's home, as well as on one occasion a coffee shop. I was aware that the informants' responses could be shaped by my age, gender,

race, dress as well as the interview setting (Denzin & Lincoln, 2003). There was little I could do about my age, being at least 30 years older than my informants, but I believed it was important that I conduct the interviews myself due to my background and relationship to some of the participants. I therefore had to pay attention to “my presentational self” (Fontana & Frey, 2003:77), establish a rapport with my informants and gain their trust. I consequently attempted to dress “down” (Bailey, 1987) that is, as informally as possible, usually in jeans, and wore minimal make-up. I stressed that I wanted to learn from my informants, that they in fact had the answers and the knowledge I sought. I believe that through the data collection process there was a gradual shifting of the balance of power between me and the informants, particularly the older ones and those where I had a pre-existing relationship. True, I remained an adult, but beyond that they were aware that they held the power in terms of *what* they told, *how much* they told, and for M. in particular, this extended to *when* it was told.

Elbow (1986, cited in Connelly & Clandinin, 1990:4) refers to a researcher playing “the believing game.” I am critical of this terminology, because by implication it does not support an equality of power: by referring to a “believing game” Elbow seems to suggest there should be a winner and a loser, a move out of reality and truth into fantasy. I believe this is the ultimate disempowering of the informant or narrator of the story, to say the listener/ researcher is playing a believing game. There was in fact a mutual shaping of the data (Meier, 1998); I was therefore as culpable as my informants in this process. I am also aware that the informants and even I as researcher have “multiple selves”(Connelly & Clandinin, 1990) and as a researcher these different selves may elicit different responses to questions. Although I certainly found that with my daughter I got a different level and perhaps quantity of data, I found all the informants provided data of a similar nature, in other words the areas covered and the stories told echoed each other.

Data emerged in a linear process (Meier, 1998) with stories being told in a chronological fashion. I found that experiences were not unique and there was a similarity in the way the stories unfolded.

3.2.2.Data set 2: Secondary voices

Other data sources included **documents** such as school reports, which reflect the teacher's voice, medical and other reports, and case history as reported by the informant. Perusal of education policy documents served to provide data about the official perspective of LD (Pillay, 1997) and the official view of the experiences of the child with LD, particularly within the education system. As for data set 1, the **researcher** was the primary instrument.

3.2.3.Data set 3: Researcher's voice

Data set 3 consisted of an autoethnography, where the researcher served as the data source. Harry (1996) and Connelly and Clandinin (1990) describe the multiple personas of the researcher. I identify four which were likely to dictate to some extent the nature of the data collected in set 3:

- The researcher as a mother of a child with LD,
- The researcher as a therapist involved in the management of LD,
- The researcher as an educator training future clinicians
- The researcher as researcher!

I have dealt above with the conflicts that arose at times because of these multiple selves. I kept a **reflective journal** which reflected not only the process of the research but my own experiences and feelings as a mother of a child with LD. This information was used to either mirror or juxtapose data collected in interviews with the children. This also allowed for me to identify, declare and reflect on my own bias as well as possible bias in the informants stories (Goodson & Sykes, 2001:25). As I wrote the dominant voice changed. I recall a reviewer comment from the first publication I had accepted. The journal's reviewer said he could sense the writer's indignation and he recommended that I rewrite the section. However it was

a tone I did not wish to change – I was indeed indignant! The many tones in the narrative representation of the data that follows in the next chapter include not only indignance but sadness, excitement, frustration, amazement to name a few.

3.3. Phase three: Data analysis

There was no definite beginning of the data analysis and writing. Even before I developed a research proposal I was in a sense writing M.'s story. This 'internal writing' in fact became the very rationale for the research. I found it necessary to develop a recognition of the importance of how my past experience influences the way I understand another's past experience, what Connor (1999:16) describes as a "hermeneutical consciousness." This is particularly important in view of my relationship to some of the participants – mother to one, friend and ex-clinician to another. I am also aware that like Meier (1998) my clinical knowledge has no doubt also shaped my interpretation of the narratives and the analysis.

The data analysis process began during the data collection phase, as emerging insights suggested direction for further data collection. There were levels of data interpretation even before data analysis began. Interpretation occurs by the informant during the telling and again by the listener/researcher in the listening (Bruner, 1986, Churchill, 2000, Goodson & Sykes, 2001). It is not possible, according to Salter (1998), to listen to a story with absolute impartiality, or "to still our 'theorising voices' as we constantly reflect and seek explanations for our own experiences in the stories of others" (Salter, 1998 citing Bishop, 1996). It was important through this first level of "listening analysis" not to succumb to the desire to ignore parts of the story told that may not have seemed useful for my research purposes (Kazmierska, 2004). Indeed there were entire themes I may have missed had I not "listened beyond the research questions," such as the type of support sought and the persons approached for that support, as well as the issue of blaming extrinsic factors, all discussed in Chapter Five (164). In fact it is just this which Huberman (1984:15 cited in Gerber

& Reiff, 1991:3) states is a strength of qualitative research: "...qualitative data are more likely to lead to serendipitous findings and to new theoretical integrations; they help researchers go beyond initial preconceptions and frameworks."

Another level of interpretation occurred between listening to and transcribing interviews (Bruner, 1986). As this is an **inductive** research process (Creswell, 1994, Meier, 1998), I found that even as I transcribed all interviews and audio journal entries I made choices about how to "clean" the data (Lemke, 1998, Plummer, 2001) by electing to keep in the interjections and hesitations where I felt they added to the text. There were times when it was clear from the hesitation that the informant was discussing a difficult or painful experience, and here I elected to leave in the "ums and ers". The interjections and nonfluency in one informant's speech was particularly important as this was clearly part of his experience of LD. It can also be claimed that analysis even began in the transcribing (Bartlett & Payne, 1997) in the way I chose to break lines and separate propositions.

According to Plummer (1983, in Cole and Knowles, 2001:99) analysis involves: "brooding and reflecting upon mounds of data... until it makes sense and feels right." In transcribing the "brooding" started and it was these early reflections on the data from initial interviews that dictated to some extent the need for and the direction taken in subsequent interviews. It is interesting that the interviews with the female informants yielded rich data almost at the outset. There was a shared vision for the research and commitment to telling the story in a "no holds barred" manner. Although this can be accounted for in part by the fact that one of the female informants was my own daughter, and therefore the relationship between 'interviewer' and 'interviewee' was not a typical one, and another of the female informants was a friend who had known me for a number of years, even the third participant, who had no prior relationship with either me or my daughter, was very open and forthcoming in the initial interview.

However the male informants were more reticent. The one, who had a previous relationship with me as I had been a therapist at the school he attended some years before, and in fact had been his speech-language therapist briefly, was extremely reticent. The planned “guided conversation” turned into a question and answer interview where answers were limited. However what was interesting was that very often it was necessary to note his nonverbal responses as these would not support his verbal response. Gorden (1980:355), cited in Fontana and Frey (2003:87) describes four types of nonverbal communication: proxemic, which refers to interpersonal space; chronemic or the pace of the speech and pause duration; kinesic which refers to body movements and posture and fourthly paralinguistic, which includes features such as tone, loudness and pitch. For informant B., who gave so little verbally, the kinesic aspect gave information, for example when asked to recall a particular grade he would respond verbally by saying he couldn’t remember, but the body movement, breaking of eye contact, agitation of his foot seemed to say “don’t go there, I’m not prepared to discuss it.” The second male informant was extremely open, but his responses were constrained by his nonfluency, word-finding difficulty and poor oral language.

3.3.1.Data analysis process

In approaching the data I tried to avoid “preconceived notions, expectations, or frameworks” (Creswell, 1994 :94) in the data analysis process. However I was aware that by making interview content data, by transcribing and even through selecting how and what to transcribe, I was already providing a specific framing for my own purpose (Lemke, 1998). The following procedures were followed in order for qualitative thematic categorization of the data to be obtained:

- Scanning and cleaning of the data:

In transcribing what was spoken in the interview and audio journals into written text for the purpose of analyzing there was a risk of “sanitizing” the text by removing the hesitations, false starts and nonfluencies. As this provided some useful information, especially for the two male informants, my initial transcriptions included all

vocalisations, and I used diacritics such as dashes to mark the duration of the pause or hesitations. I found this meaningful especially for the two male informants. Informant A. presented with nonfluent speech due to word finding difficulty, which resulted in false starts, re-starts, hesitations, ellipsis and even ungrammatical sentence forms. However the meaning of the message was apparent. In B.'s case the verbal response was at times inconsistent with the nonverbal, for example he would say he didn't remember an incident but body movement, breaking of eye contact and even his eyes tearing up sent a different message. As three of the informants became tearful during the interviews, I used a symbol in the transcript to denote tears when this occurred.

- Thematic analysis:

Identifying the “smallest elements” without losing meaning: these meaning units (Ely et al., 1997) were of varying lengths, ranging from single words to phrases or even paragraphs. Such elements included identifying “moments” e.g. happy moments, distressing moments, moments of shame/ embarrassment (Alant, 2003)¹⁹

- Units were then coded (Creswell, 1994 :156).

I developed a story matrix ²⁰ which served as a framework for the initial analysis. These matrices were then used in constructing the stories. The initial elements were sourced from the literature (Alerby, 2003, Augur, 1995, Doherty et al., 2000, Frank, 2002, Riddick, 1996), and then additional elements were added as I went through the data. This became an iterative process: new elements or units expanded the matrix, and I then went back to each transcript with the expanded matrices and looked for similarities across stories, and shared experiences. Themes were identified.

- Thematic categorization:

Categorisation for sorting had to be flexible with the organizing system dictated to some extent by the data generated and by the patterns of experiences that were noted (Creswell, 1994 :157). Like

¹⁹Dr. B. Alant Personal communication Seminar series 7/06/03

²⁰ Appendix III

Connell, Lynch & Waring (2001), I developed initial themes from the literature, and developed others as they became apparent in the data.

One area where I exercise caution is, that whilst I accept and even “embrace” the subjective nature of this research, as discussed above, I have a commitment to tell the insider’s story, not mine. The importance of plausibility, authenticity or verisimilitude (Connelly & Clandinin, 1990) is paramount. Therefore in writing up the data I was constantly mindful of the danger of my voice predominating (Mehra, 2002). During the writing up of the report and representation of the data, in attempting to establish the veracity or truth of my analysis and conclusions from the data I would frequently set up an iterative process with two of the informants with whom I had frequent contact: my own daughter being one.

3.3.2. Data analysis tactics

Multiple analyses of the same data were done, utilizing the following tactics:

- Factoring data into themes;
- Data clustering or grouping of similar data;
- Weighting the data – data set 1 was given more weight, considered stronger than sets 2 and 3 in order to privilege the child’s voice.

3.4 Drawing conclusions: Data interpretation

Data were interpreted on multiple levels. Throughout all levels of interpretation it was necessary to refer to informants to go through the stories together, developing credibility through validity checks (Creswell, 1994 :158, Guterman, 1995) and establishing plausibility, authenticity and dependability (Connelly & Clandinin, 1990, Denzin & Lincoln, 2003). I can lay claim to “truth” through the process of member checking (Kazmierska, 2004). In other words the stories told in the following chapter have been validated by the tellers of the stories, as the informants were asked to agree that what was written was consistent with what was told. It is

important to note that findings of such a study cannot be generalized. The nature of the research is such that I cannot make assumptions about generalizability and validity of the stories. This terminology is however is not used in the dominant discourse about qualitative research, particularly narrative inquiry. The selected methodology “aims to uncover the complexities and contradictions in people’s lives, rather than represent an uncomplicated and generalizable truth” (Salter, 1998:17). However in identifying themes emerging from the data, particularly themes that have not been accounted for in the existing body of research in the field, “limited generalizability” (Creswell, 1994:159) might be possible. It was also incumbent on me as researcher when analyzing the data to ask why each informant chose to tell those particular stories (Kruger, 2003), because in attempting to answer this question another level of insight is added.

A critique of narrative inquiry is that the research may deliberately or unintentionally fake the story (Connelly & Clandinin, 1990). It is incumbent on me as researcher and writer to reveal at this point choices made about stories told and stories left untold. I am aware that in my initial setting up of the interviews, and in the background given to informants about the study, I was already providing a possible framing for their stories, even perhaps limiting what they chose to tell. I am mindful that the story each informant told me at the time was perhaps not THE story, but A story; or this was THE story they wanted me to make public.

3.5. Data representation

Noy (2003) suggests that a dissertation could be seen as a journal, a “scholarly diary.” I have chosen to write this report in a personal style, not only for this reason but because I believe this is consistent with the paradigmatic framing of this work. Data are represented in narrative form. According to Polkinghorne (1988:18):

Narrative ordering makes individual events comprehensible by identifying the whole to which they contribute. The ordering process operates by linking diverse happenings

along a temporal dimension and by identifying the effect the one event has on another, and it serves to cohere human actions and the events that affect human lives into a temporal gestalt.....By inclusion in a narratively generated story, particular actions take on significance of as having contributed to a completed episode....The means by which specific events are made to cohere into a single narrative is the plot or storyline.

Presenting data in a narrative form not only links events into a cohesive whole, it also makes allows for breadth of data (from the number of informants), insightfulness (due to my literature review, peer review and professional history in the field) and coherence (by maintaining the focus by constantly bringing the narrative back to the informants' experience of LD) (Robertson et al., 2005). Noy (2003) suggests narrative research allows one to move beyond a focus on fragmentary skills, a view also held by Jones (1993), and this is what I set out to do, as outlined in the introductory chapter.

The stories have been generated in an inductive way, in other words allowing the data to speak for themselves (Connelly & Clandinin, 1990).

I have used extensive quotes in both the presentation of the stories in Chapter Four and in the analysis of this that follows in Chapter Five. This is in an effort to remain true to the informants, to provide *their* truth, to allow them to speak for themselves. However this is presented within a framework developed by me as researcher for the purposes of theorising (Meier, 1998).

Instead of telling a life story in the typical sense, I have told a story of a life so far, and my focus has been on a specific period of that life: that period from preschool to high school, which for most of my informants was where their lives were during the data collection process. I have then attempted to emplot the story by bringing together multiple events and giving them meaning within a time frame (Ricoeur, 1991:20). What is constructed is a "descriptive narrative, a synthesis of knowledge about the phenomenon under study" (Creswell, 1994:162). I therefore present that data in Chapter

Four in both an inductive and a demonstrative way; the latter refers to my use of data to exemplify my thoughts and argument (Connelly & Clandinin, 1990). I take a sociological approach to the texts which Ryan and Bernard (2003:259) describe as “[treating] texts as windows into experiences.” In finally presenting my arguments in Chapters Five and Six it was important for me to use extensive quotes from the interviews (Meier, 1998) despite also generating the narratives as a way of presenting the data.

4. Ethical measures

The research proposal was submitted to the research and ethics committee of the University of KwaZulu-Natal (formerly University of Durban-Westville) and granted ethical clearance (Number 03011A)²¹.

Informed consent is a critical ethical issue, particularly as the research participants were children. There is, according to Norwich and Kelly (2004), an increasing recognition that children can be seen as experts in terms of what they can contribute as participants in the research process. It was this view of children as experts that I felt was essential for this study. One of the informants was my own child. The issue of informed consent in this case warrants some discussion. How does one ensure that consent that is given from one's own child is “informed” and is her will? In this case my daughter was so much a part of my early musings around her experiences. The inevitable move into formalizing those musings into research questions involved discussion around alternative ways of collecting the data and various data sources. At that point I asked her how she would feel about being part of the sample, including whether she would prefer a different interviewer if she did decide to participate. The discussion was ongoing, and I believe she was provided with sufficient opportunity to withdraw from the research, or to terminate the data collection; perhaps this is a naïve view. How does any parent get informed consent from a child? As with all my informants, the ultimate decision to

²¹ APPENDIX IV

participate was hers, although I have no doubt parental guidance, or perhaps even influence, played a role in this decision.

All potential participants, or informants, were counseled regarding the nature and process of the research and through role play activities went through “trial interviews” (not for data collection), to allow them to experience the process. Prospective informants were then invited to participate. Goodson and Sykes (2001) recommend any research participants receive written information regarding the proposed research. To this end, I gave parents of all informants an abridged version of the research proposal outlining the rationale, methodological processes, time lines as well as my own expectations as researcher in terms of participation, and assurance of confidentiality. I felt it was imperative that both parents / care-givers and children give informed consent and that the informants not be selected purely on parents’ consent.²² Furthermore I made it clear that informants could withdraw from the research at any stage and that they would have full access to all information used in the research prior to submission or publication. Kazmierska (2004) raises the ethical issue of the informants’ understanding of how their story will be told or used. This was particularly important in this study again as my informants were children who may not have understood the complexities of text analysis. I endeavoured to address this before the research process by explaining that I would attempt to write the story of their school experiences based on what we discussed in the interviews. Once the stories had been constructed I then went back to my informants to review the story, reflect back on the data and engage in member checks.

Confidentiality was ensured and neither the schools nor the individuals were identified in any way in the research report. I performed what Bargdill (2000:193) refers to as an “edited synthesis,” where all information that would identify informants is omitted, names of informants, schools and teachers have been changed.

²² APPENDIX V

5. Conclusion

In the following two parts of this research report I present the data and develop theory from the data. In Chapter Four I tell each story using a chronological outline (Chanfrault-Duchet, 2004, Connelly & Clandinin, 1990). In Chapter Four where I present the stories, I have attempted to stay as true to the informants as possible by using their own words as much as feasible. However in Chapter Five I invite the reader to share what I see in the stories. I hope that like Peshkin:

When I disclose what I have seen, my results invite other researchers to look where I did and see what I saw. My ideas are candidates for others to entertain, not necessarily as truth, let alone Truth, but as positions about the nature and meaning of a phenomenon that may fit their sensibility and shape their thinking about their own inquiries (Peshkin, 1985, cited in Connelly & Clandinin, 1990:8).

I make the researcher voice central and this aspect of plurivocal researcher (Barnieh, 1989, in Connelly & Clandinin, 1990) is me as theory builder as I present what I see in the stories of my informants. I review and analyze the data and here I have used my “multiple selves”: educator, therapist/clinician, friend, mother, as each one has seen something different in the data.

PART TWO: The product

*being the
manufactured goods,
the creation,
the invention,
the results,
the outcome*

in which I present the photograph

CHAPTER FOUR

DATA PRESENTATION: Displaying the photographs

In the previous chapter I detailed the research design and methodology and justified my choices. I provided a detailed description of the data sources and how I set about analyzing the data. In this chapter I present the data in storied form. I present five stories – narratives based on the data obtained from the sources described in the previous chapter.

1. Introduction

Aristotle did not hesitate to say that every well told story *teaches* something; moreover he said that the story reveals universal aspects of the human condition (Ricoeur, 1991:22). Each story that follows is a composite account of the experiences of a child with learning disability. I have in parts therefore “fictionalized” the facts (Denzin & Lincoln, 2003:17, Holt, 2003) and have attempted to write what Connelly and Clandinin (1990) call “invitational narratives:” those that invite the reader in. The events and incidents described by the informants in the interviews and journals are linked to form a coherent plot (Polkinghorne, 1988). To this end I have constructed the stories chronologically to give them some structure. Each story hangs on the following “pegs” or key events: preschool, early school experiences, the awareness of difference, the “diagnosis,” experiences of failure, exclusion, change and finally “surviving LD” or acceptance. Needless to say all these framing concepts form part of the informants’ understanding or interpretation of their condition. Thus these stories give the reader insight into how these children respond to external labeling.

I have italicized where I have used the informants’ actual words, and the rest of the text is my paraphrasing of their words in some instances, and a filling out and linking of data in other instances, in order to develop a cohesive narrative. Where I have done the latter I have used my own knowledge of the context, the informant or the full data pool, to provide

links that are consistent with the story generated by the informants. Although the presentation of the analysis follows in Chapter Five, I acknowledge that a level of analysis already occurs here: my attempt to turn the informants' stories into coherent, intelligible, and structured narratives, is in itself an act of analysis and interpretation. Essentially what is presented in this chapter then are interpretations of interpretations. There are instances where I have included insights specific to a particular informant's story, instances where I believe an additional comment or explanation is warranted outside of the more structured analysis chapter, or where I believe insights from my researcher's journal are relevant to the story. I have added these as 'boxed footnotes' which then does not break into the narrative at all, and allows for a 'reading of the story' as it stands. However the footnotes are there to provide that extra commentary as an aside. In an attempt to keep the voice as authentic as possible I have used the informants' actual words as often as feasible. What I have woven here from my data could be any child's story.

I have elected to write the stories in the first person for two reasons, both deeply personal. At the outset of this research I promised to tell the stories of my informants, stories of those without a voice, stories of the children who experience their LD daily, often in a world on the margins. As I read through the transcripts of the interviews I was pulled deeper into that world, at times marveling at my informants' insight, their matter-of-fact way of handling adversity and at times weeping for their pain. By writing in the first person I get a deeper sense of that world. I aim by writing this narrative in the first person to put the reader into that world too, for the reader to become the "I" in the hope that the researcher persona becomes invisible, and this narrative becomes a dialogue between reader and child with LD. There are experiences that are common to all participants and therefore a reading that results in the sense that each child's experiences blur into the others could provide a useful, composite picture of what it's like to "be /have" LD. I am aware, however, that to write each story in the first person could make the reading difficult, even confusing. Many of the experiences of my informants are similar, and it is this very similarity that

is important for my thesis. However it is that similarity that makes for repetitive story-telling. I therefore debated whether to write the stories 2,3, 4 and 5 in the third person in order avoid repetition and confusion for the reader. I believe this would defeat the purpose of writing the “invitational narratives” described above.

Another reason for considering using the third person in stories 2-5, is that gender of the informant would be apparent. While my initial intention was to highlight gender differences, it can be seen from a reading of the following stories that in fact there are far more similarities than differences in experiences, and where there are differences in either experience or telling of that experience it was not issues such as gender or even degree of LD/ extent of difficulty that separates them. Rather it is issues such as access to special education, acceptance of the LD and the extent to which this is embraced as a part of the informant’s identity. Thus I have consistently written each story in the first person, to provide the emic view, or the actor’s perspective (Denzin & Lincoln, 2003:16).

The first story is more detailed and therefore serves as the “core” narrative, and it is in many senses an autoethnography. This story is detailed and contains elements that are absent in the others purely because the data collection process has been ongoing: this is my own daughter’s story. The subsequent stories are really there to support the core narrative.

2. Michelle's story :

Michelle was 14 at the time of the first interview. She is the youngest of two daughters from an intact, nuclear family unit. She has had a typical, sheltered but privileged middle class upbringing. Not long after she entered the formal school system, in grade 1, it became apparent that she was not coping well. The early history is detailed in a letter I wrote to myself in my research journal and introduce here as background to Michelle's story:

Letter from a mother,

*I am Michelle's mother. She is my precious child –
my second born, my baby,
my butterfly,
my difficult one, my impulsive one, my streetwise one,
my mature one, my loving and affectionate one,
my sensual one,
my chesty one, my active one, my giggly one, my silly one
my special one.*

Michele's early history was uneventful and she reached all her milestones well within the expected time frames. Once she was mobile the stress really started. She climbed the burglar bars and security gates at the door with ease, and on more than one occasion was found in some precarious position and in physical danger. None of the things she did were in and of themselves 'abnormal' or 'different' - it was just that she seemed to do them more often, and more intensely than other children her age. I never considered that this early behaviour may be an indication of an attentional problem.

She went to playschool and then preprimary where there were no problems. It was only when she began formal schooling – grade one – that her behaviour started to suggest that she was not coping that well. She seemed

more than ready to start school and went off wildly excited about being in “big school.” However before long the expected excitement at learning to read and write had become instead an elaborate set of homework avoidance strategies. Then the stories of tears at school, of having to stay in at break to finish work and of the teacher’s comments about “crying again” started to filter home. I do have to say that what angered me most during this time was that there was no concern expressed by the teacher, no call to the school to discuss Mich’s obvious unhappiness, no mention that progress was slow, until I initiated a parent-teacher meeting. From that meeting it became apparent that teacher had pigeon-holed Mich as the “cute blonde who is not quite as bright as her older sister” (by this stage her sister Beth, who was two years older than her, was already a high achiever known to many of the primary school staff). In fact I still feel my blood pressure rise as I recall the teacher’s words to me: “She’s not Beth you know.” The implication was that I was expecting too much of this child who, after all, was not going to achieve as well as her sister. This pronouncement was made by a teacher who had never taught Beth and had had Mich in her class of nearly 30 children for just 6 months. It was – and remains – an indictment on the teacher concerned that an educational psychologist who assessed Michelle suggested her intellectual potential fell in the “superior” range at the time.

We were fortunate in that during that period I was professionally involved at a multidisciplinary assessment centre and was able to have M. assessed by an educational psychologist, a speech therapist and an occupational therapist, all of whom I knew and respected for their professional insight.. The assessment team was, in many senses, handpicked for their respective strengths and abilities to relate to the sensitive child M. had become. I am aware that perhaps one disadvantage of this is that findings and even wording in reports may have ultimately been shaped by my relationships with the professionals concerned – I like to think though that each was professional enough to look beyond friendship and to what was really in the best interests of the child - of Michelle.

The outcome of the assessment was interesting to say the least. It was a relief to me as a speech-language therapist to see that there were no problems in this area apart from some slight but insignificant weakness in auditory perceptual skills such as auditory analysis and synthesis (an essential prerequisite for learning to read and spell). It was also noted that there was a significant 17+ point discrepancy between verbal and nonverbal IQ, (the tool used being the Junior South African Intelligence Scales) with the former being very strong – in the superior range, and the latter being weaker but still in the average range. In fact Michelle's rote memory for digits repeated forwards and backwards was outstanding , with the psychologist commenting that she had never had a child with full recall on this subtests, a feat M. managed . The OT assessment revealed very specific difficulty with crossing the midline, spatial perception and sensory integration.

I was working part-time in a remedial school at the time, and this too seemed serendipitous. It appeared from her assessment that she was an ideal candidate for the intensive, short-term scholastic and therapeutic remediation the school specialized in. The timing was perfect –the end of her grade one year, and there was a vacancy in the grade two class for the following year. After the multidisciplinary team at the school discussed the above-mentioned assessment reports and her school report, she was accepted into the remedial school .

I am aware that our journey to this point had been so different to many other parents'. I had the appropriate support from colleagues, the experience and insight to know how to deal with the problem in terms of having M. assessed, where to have her assessed and what to do with the assessment results. Many other parents are not so fortunate and do not have such a straight-forward journey with their children – neither do their children who experience repeated failure, sometimes punitive treatment from parents and educators who may not understand what the child's

difficulties are and then the endless battle to find the appropriate management for those difficulties.

Sue started at Ridge Remedial in her grade 2 year, having met the requirements to pass from grade 1 despite her difficulties. I had been warned by the teacher at her mainstream school not to look for problems where there weren't any and was also told that my professional background may be impairing my judgment. I remain convinced that it was that professional background that saved Michelle the trauma of repeated scholastic failure. In her first week at the remedial school her teacher came to me with a piece of written work Mich had done and said "Penny, if you had nay doubts about this being the right place for Mich, look at this. I can't believe her teacher didn't support this referral". I will never know how Michelle's academic or scholastic career would have progressed had we not moved her or had we waited for her to fail outright (which I still believe was inevitable). What I do know is that Michlle benefited immensely from the input and support given during the two years she spent in the remedial environment. Michelle's dad, like many fathers I have interviewed in my practice, had difficulty understanding how a child could be highly intelligent but not be able to read or spell, how an apparently bright child could not give directions to a friend's house or tell left from right. I know there were times when he thought she had to be putting it on – when he just couldn't believe she thought that to get from point A to point B we had to pass points X, Y and Z.

Michelle's experience, including her time at Ridge Remedial, is best described by her, and is done in the narrative generated from the data. The data on which the following narrative is based come from multiple sources. She was the only informant who chose to write as well as keep an audio journal. She expressed a preference for writing which was unexpected given the assumption that written language is usually tedious and problematic for children with LD. Other data come from interviews with her, her audio journal as well as sundry visual / pictorial data such as a

painting and a collage she chose to submit. She is bright, articulate and very open about her feelings and experiences.

I have added in notes or comments in parenthesis where relevant information is presented that did not emerge from these specific data sources, but rather as a function of our relationship and the fact that I see her everyday. Some days she would come home and recount an experience she had had at school and this information would not be presented in her journal or did not emerge during an interview. However I have included it due to my own subjective view of its relevance to the main concerns of the story. I acknowledge that in so doing I have already analyzed data by deciding what to include and what to exclude, and therefore present a truth as I see it.

Michelle: An impressionistic tale²³

Wow *surviving school* –that’s how I see it. Surviving *workload*, *figuring things out*, *studying* hard: it really is *stressful*. I know I’m *smart*- I know that now anyway, but it took me a long time to realize that. For many years I felt like an *outcast*, and if I’m really honest there are times that old feeling creeps back. I don’t find it easy to concentrate to *focus* in the classroom and in school where everything seems to be about achievement and marks and *percentages*. If I’m asked to give one word that reflects my early school years at least I’d say *everyday blues*. Perhaps to clarify I should start at the beginning.²⁴

As I think back on my school life so far, it is hard to remember the beginning. When was the beginning – grade one? Preschool? I don’t remember much before grade one but I do remember being happy and having friends. Although I do not remember specific things about preschool, I enjoyed the lack of structure, the chance to play both inside and outside the classroom. It is really only entering the more formal school system that I remember. I certainly remember grade one as though it were yesterday. Grade one was a very difficult year, *I would say it was the worst year*. All the excitement of going to “big school” had dissipated by the end of the first term and by the middle of the year school was not a happy place to be. I wasn’t able to complete tasks in the time allowed and so the teacher²⁵ *used to keep me in the classroom during break* in order to complete my work. I felt this was a punishment because *all the naughty kids had to stay in at break*. It made me feel that my behaviour was bad, that not finishing my work in time was because I was naughty. I tried so

²³ GEELAN, D. R. & TAYLOR, P. C. (2001) *Writing our lived experience: beyond the (pale) hermeneutic?*[online] Available from <http://unr.edu/homepage/crowther/ejse/geelanetal.html>. [Accessed 30/11/2005].

²⁴ This part of the narrative was developed purely from a collage M. submitted. This collage appears on page 205.

²⁵ In all her references to what was clearly a traumatic year for her, the informant from whom this data was taken never names or ‘personalizes’ (? humanizes?) the teacher- she never uses a name or even the noun “teacher;” she is always only referred to in terms of the third person feminine pronoun, “she.”

hard I was exhausted by the end of the school day, but still it didn't seem to make a difference.

It seemed to me like everybody around me was ten times smarter than me and they would know things and I wouldn't know. I felt like I was the only person in the class – even the school – who was having difficulty. The only thing I could do reasonably well was sport, and in grade 1 it is not very competitive anyway so I didn't really have a chance to show a strength.

*I can remember one thing in particular we had to do-it was a test and we weren't allowed to rub out what we had written, and we were supposed to write "son"- not the sun that shines in the sky and everybody knew that it was S-O-N and I didn't. I wrote S-U-N. I felt so stupid because everybody else had got it right and I didn't and it was such an easy word. I am not sure whether I knew how to spell it and just wrote the wrong word, or whether maybe I thought that was how to spell "son". All I can remember now when I think of that time is that I got it wrong and how I felt at the time. Another incident I remember from that time was when the teacher put up some cards for us to read and she had **put** and I read **putt** and everybody else knew how to read the word and I didn't. I was in the bottom reading group and I didn't like it. Even now as I think back on that time I feel close to tears - it brings back such painful memories*

I became increasingly anxious and afraid of doing things at school in case I did them wrong. The anxiety exacerbated the problem as this slowed my work rate even more. The teacher shouted at me –I remember she was always shouting and unhappy. I also remember crying nearly every day at school. The teacher teased me about always having tears in my big blue eyes, but she never seemed interested in why they were there or how staying in at break every day made me feel.

As the year progressed and the homework load increased I hated school but I hated the afternoon at home even more. I did everything I could to avoid doing homework, and when I finally sat down with one of my parents

to do the homework, I would ask questions about all sorts of things to keep them talking instead of practicing reading or spelling. They would patiently answer my questions for a few minutes, then it would be “Come now let’s concentrate S. Look at the book, not out the window.” Oh how I hated that word “concentrate.” It seemed it was all I heard. I loved stories but reading them for myself took so long. We had to learn phonics, practice sounds, and I would practice until I knew them, and then at school the next day when the teacher asked what they were I would forget, or I would just sit quietly and not even try in case she shouted at me. I was so scared of her.

I really believe *I didn’t really learn that much there* that year. By the end of the year I had gone from the happy little girl with many friends that I had been at preschool to an anxious, withdrawn and introverted child. I felt desperately unhappy and alone. By that time my parents had started to think I needed more support than I was getting at school and had me assessed. All I remember of that time was that it meant a day off school and I was happy to do anything if it meant I didn’t have to go to school. I didn’t fully understand the outcome of the assessment but I do remember my parents telling me I was going to a new school for Grade 2. They explained that it was just something they wanted to try. I think *I think I knew it was because I couldn’t cope* or at least *that’s how I understood it* at the time.

Initially I was quite passive about the move. *It didn’t seem to bother me, nor do I remember being excited.* As soon as I got to MP I realized *it was a much better environment for me. It was difficult at first and I felt very insecure* because I didn’t know anyone there. That didn’t last long though and I met my best friend just after I started there. I remember walking into the classroom on my first day, feeling so anxious and afraid, and the teacher said “*Ah there’s a smiley face you can sit next to.*” She put me next to H., and that was the beginning for me. *I remember my first few days were really hard because I wasn’t used to it and everything was so different.* It got better and within a few weeks *I was much happier there, it was just having friends and it wouldn’t matter if I didn’t know and just said putt*

instead of put. I felt a sense of “sameness” instead of feeling like the *only one who didn’t know* things. My experience during this period was not of difference or alienation because my performance and behaviour did not stand out as “different” in comparison to the behaviour and performance of the other children in my class. Before long *I felt comfortable there* and had many friends.²⁶

The one thing that sticks in my mind about the move to remedial school was the teachers. They were all so kind and *they made everything so enjoyable. Everything just seemed to be fun.* I never felt “*ah, it’s work again.*” I learnt so much there and *I can still remember* things have just *stuck in my head.* The teachers were *gentle*, and didn’t shout. They understood if you had to leave the class for occupational or speech therapy and *if you were not there to do a test they’d wait until you were back* because they knew you were there in that school to get all the support they could provide.

One of the big differences for me was that I was no longer afraid of writing in case I spelt a word incorrectly. *I could go to the teacher and ask her to spell any word* and she’d help me spell it. *I used to love story writing*

²⁶ I describe the period at remedial school and the subsequent return to mainstream in my journal:

It was a time when I was relatively uninvolved as a parent as I spent those two years completing a Master’s degree. The onus fell on M’s dad to check and provide homework support, a task he took over with good grace. I do know that over those two years M. grew from a timid, ready to weep at any moment, permanently exhausted little girl into someone who read for pleasure, loved her teachers and started to find her own strengths in art and creative writing. I will never forget the day I walked into her bedroom and she was lying on her bed reading her Bible. It was not the easiest choice of reading material, and certainly not something she had been instructed to do, but she had chosen to do it. When I sat down to talk about what she was reading, half expecting her to quote verses verbatim with little insight, I was astonished to realize she was understanding what she was reading and she was reading for pleasure. It was in many ways the memory I hold onto as being the clear indication that she was going to be “ÖK”(whatever that is!)

because I had the confidence to use any word I wanted to, whereas before I only wrote what I was reasonably sure I could spell. Because of the teacher support *I didn't actually have a problem spelling.*²⁷

I learnt to be competitive there. *I can remember a competition where the challenge was to beat Peter and Graeme in task completion; they were the two fastest workers in the class.* I realized I had the ability to compete and be *near the top of my class.* I loved the competition and the fact that I could compete. It was something that really developed later when I got to high school. I still think back on those times as the best school years, and *easily rate it 8 or even 10 out of 10.* There was a lot of homework, make no mistake, and there was pressure and challenge but what I really recall was the fun we had there.

After completing two grades in the junior primary phase and receiving intensive remediation in a specialized environment, I returned to mainstream.²⁸

²⁷ It is interesting that she used to love story writing. Written language and spelling are two primary areas where children with LD have difficulties and M. is no exception. Yet she felt positive about it, and not constrained by an inability to spell. The support provided by the teacher was never judgmental, in other words no matter how often a child would ask for help, or how “easy” the word was, the teacher would provide the necessary support.

²⁸ *When the time came for Michelle to return to mainstream we discussed a number of options with her, realizing that she might not want to return to the school where she had had difficulty in the past. However she opted to return (much to our relief as it was conveniently close to home) and to their credit that school staff for the most part taught her with insight and sensitivity. She was especially fortunate to have as her grade 4 teacher a very creative, artistic young woman who continued to nurture her creativity and especially her love of art. It was by no means plain sailing through the rest of the senior primary years but Michelle coped well and in fact achieved far more than was initially expected. She really only came into her own though in high school. We were fortunate to be able to send her to a private school where the classes were smaller than in the mainstream and the entire high school only had +/- 400 pupils. It was a school where the individual's strengths are encouraged and nurtured and where there is not a huge focus on academic achievement, although the academic standard was high. The ethos of the school was, at that time, nurturing and family oriented. Although Michelle's older sister attended the same school, it did not take long for educators to realise that Michelle was not a clone of her sister and to treat her as an individual.*

Actually returning to the school where I had had such an unhappy first grade was something I discussed with my parents at length. We fortunately lived within 5 kilometres of three very good government (state) schools, and I was really tempted on leaving Ridge to go to a completely new school. I visited all the schools but in the end decided to go back to where I had started. The decision was made partly because I felt at least I knew the school and it would in a way be a going back to where I belonged rather than another new start. As it happened it was a new beginning and once again I felt like an outsider because *I didn't really know anyone and nobody remembered me*. I had been at the same school in my first grade. I had to make new friends all over again. I found it difficult adjusting to a new school and making new friends. *It was hard* even though *but there were a lot of new people because I was going into grade 4* and other children came into the school from different junior primary schools. It means I was not the only one who was new to the school or even the class at the beginning of the year, and we all had to make new friends. Once again I felt I was in a place where *no one would understand* the difficulties I had or how hard I had to work to keep up. There were so many times when I felt *I didn't understand what was going on and everybody else did*.

There were subjects I *really liked* and did well in though, like *maths*. *I can remember changing maths classes -I was shunted up from the D class to the B class*. Perhaps I'd been put in one of the bottom classes at first because I was coming in from a remedial school, I don't know. Anyway I felt quite indignant at the move and didn't see it as a reward or in a positive light at the time.

I remember feeling under so much pressure to keep up with the class. I was so afraid I wouldn't be able to fit in that I pushed myself to stay with the group and not fall behind. On one occasion we had *a geography test that I had not prepared for*, for a number of reasons not the least of which was the fact that geography just never made sense to me. Anyway on the day of the test *I had the notes in my desk so I put my rubber in my desk so I could open it to look at my notes*. I am so embarrassed now by my behaviour, and

even feel emotional recalling the incident. Naturally the teacher saw me and *called me up in front of the class and she asked me why I hadn't learnt*. Then she *said she'd leave the mark on my report and I'd always know that it wasn't my true mark*. Well needless to say *I never ever cheated in a test again. I learnt then that it was just like not a very clever thing to do*.²⁹

In grade 6 I began taking medication to help with my concentration. At the time I didn't tell anyone. I was – and still am – very *sensitive* about this and am aware of people's attitudes towards Ritalin - *its amazing how ignorant people are – they read one article and then they think they know everything*. I've heard friends saying things like *it makes you really high and its addictive*. *The ignorance just annoys me* and that is why I still don't tell friends I take it. I suppose my teachers have to know, but I think they also *think about you differently* when they know³⁰.

²⁹ Fontana and Frey (2003:87) cite Van Manen's description of a "confessional style" of journal writing which allows for "...soul cleansing by researchers of problematic feelings and sticky situations." I do just this in the following, the entry I made in my research journal immediately after the interview which yielded the 'cheating story':

It was very difficult listening to this confession as I was completely unaware that it had ever happened. As I think now on M's courage in mentioning it, 2 things strike me – the most powerful is that the interview really was not between mom and daughter – that M was able to talk about the cheating episode so honestly 6 years after it happened suggests she was unlikely to ever tell me as her "mom", yet there was no hesitation in talking about it in the interview. The other thing that struck me was as she cried, my instinct was not to reach out and comfort her as her mother, but to lean forward with the tape to make sure this 'data' was captured. That is a confession I have to make and one that I am almost afraid to voice. It has thrown light on the Researcher-mother / Mother-researcher identity and it seems at this stage the mother is not the dominant one.

³⁰ *On one accession M had to be excused early from school because she had a follow up visit with the paediatrician who was monitoring her on the medication. She was extremely angry that the teacher had been given the reason for her early departure from school, and felt it was none of her business.*

By the time I had reached grade 7 I was ready to move on to high school. I felt the work *wasn't intellectually challenging for me* and although there *was a lot of work it wasn't that hard for me*. It wasn't all plain sailing though. There were times when I was so frustrated. There were times when I felt I was the only one who did not know how to do a particular exercise, or know a particular answer. I would feel like such an idiot, but no one ever made fun of me or teased me.³¹

The move to high school was one I remember vividly. Once again I had three options: two local government (state) schools, and a private school. The two local schools were each within a 7 kilometre radius of my home but were very different: both were girls' schools, one priding itself on academic excellence and the other offering interesting alternative curricula like catering and travel and tourism. Both were large by local standards: each had over 1000 learners from grades 8-12. As cooking had by this stage become my passion I was very tempted to follow the catering route. Again my parents presented me with the alternatives but left the decision to me. Ultimately though I decided to go to the smaller private school for two reasons: one, it was co-educational and two, it was much smaller, with only 400 learners in the high school at that stage.³²

One disadvantage was that my older sister was already at the school. I say this was a disadvantage for me because she is a high achiever academically and I had sometimes felt in her shadow in primary school, especially when teachers commented on her abilities or called me Beth instead of Michelle. It made me feel they were judging me by the standards she set instead of as a different individual. I hoped that with the different way of teaching in

³¹ Teasing was quite a problem for the other 4 informants though. See chapter 5

³² *This decision took a few months to make, and it was in fact only made on the closing date for applications to the private school. It is a measure of an emerging confidence that M. chose what clearly was going to be the more difficult route academically, with the private schools at that time writing different national school leaving exams, touted as being of a higher standard.*

high school and being exposed to far more teachers I would be lucky enough to get teachers who hadn't taught her and therefore would not be tempted to compare.

Once I got to high school, a new school again, *I made friends quite easily*. I was in with a group *who really wanted to work* and that was great. I made friends with people who were achieving better than me at that stage. They pushed me indirectly I guess. I also pushed myself and set goals against what my friends were doing. Because they were all such high achievers I really worked hard to keep up. The strange thing was I never felt a failure next to them. I always just felt I had to work harder until I was achieving comparable marks. The interesting thing was that I did manage to keep up and perform as well as them and in some subjects my marks really started to climb despite *the jump in the workload*. I really feel my friends *were a good influence on me because* for example *if there was a test coming up they would be learning and would even help me through things I didn't understand. It sort of shaped the way I saw things*.

One other significant change in high school is that we were streamed academically so the groups were not *mixed abilities which was nice for me because* I was in the top set for many subjects and *everybody there wanted to work, they didn't want to mess around*. It meant I *could get on with it and concentrate because there wasn't much distraction like background noise. In the mixed abilities class there were people that didn't really care about school and they would just spoil it for everybody else because they would just interrupt all the time and disrupt and fidget* which would make it very difficult to concentrate and would also distract the teacher.

I find it difficult to concentrate at the best of times. At a recent *athletics day I was running the 800 metres* which meant I had to run around the field $2\frac{1}{2}$ times. *I ran around $1\frac{1}{2}$ times and I thought I was finished. I'm quite a competitive runner – I enjoy it and I overtook the second person so I was coming second and I just stopped running! I felt so stupid, like such an idiot and I spoilt the whole race for myself. I might have actually stood a*

chance of finishing in the first three if I had just listened to instructions and followed them properly.

I've now selected the subjects I am going to do for matric³³ and that has really made a difference to my marks. I am enjoying *being able to be good at what I'm doing*, so for example *when I write an essay in history I know I'm going to get a reasonably good mark*. By contrast before being able to select my subjects and I had to for example do geography *where I was absolutely useless, it wasn't cool*. I am *feeling better about myself because of better marks* I'm getting because I'm doing subjects I enjoy and that cater to my strengths. I am doing *history as it's a very useful subject, and accounting because I've always had a thing for money, and science because it just opens doors for further study*. I do plan to continue with tertiary education once I leave school.

Although I managed to do very well at school in the way achievement is measured in terms of school tests and exam marks, for me the greatest pleasure was socializing. The most enjoyable part of my school day was the *bus ride* to and from school. We'd be able to chat, catch up with who was doing what. As my "bus friends" were not the same people I would sit with at school – most weren't even in my grade, in a way having "bus friends" and "school friends" broadened my circle.³⁴

I must say when I look back on the very difficult beginning of my schooling and look at where I am now, I feel so different. I was so unhappy in the beginning, and have so many memories of feeling embarrassed or

³³ Matriculation or school leaving exam. In South Africa at that time, learners made a selection of at least 6 subjects to study from grade 10 to grade 12 level. The requirement was at least mother tongue and one other language, as well as a selection from various packages offered, depending on resources and demand. Mathematics was a third compulsory requirement in most schools. Up to grade 9, all learners in a grade did the same subjects to allow all to experience different options before making their final choices.

³⁴ The issue of friends was very important to all my informants, contrary to research that suggest that children with LD and ADHD have difficulty socializing

feeling like I was the only one who found things difficult. So often I felt alone and different. I can honestly say I don't feel that now. *Now I don't really think of it as a problem at all- it's not that big an issue to me at all.*

Sure there are still days when things are difficult – *you know on the days when I don't take my tablet or something happens and I feel you know there it is shining through.* On those days *I think the only reason I'm in the top set – the only reason that I have an academics badge- is because of some drug.* On the whole though I don't think *its been a huge thing for me* that has made me feel *I'm special and I'm different.* My problem as I see it is *I'm not actually good at anything—I've tried a lot of things but I'm not.* *Most people that I know have discovered something they're really particularly good at but I haven't –I'm probably the only person I know that hasn't.*

Postscript:

I add here by way of a postscript an entry from my research journal which describes a conversation I had with Michelle as grappled with the data analysis.

M. has been a co-constructor of my story as researcher, and long after the data collection period has ended remained a “data source.” I continued to seek her view, even her approval, as I wrote up the final chapters. There were days when, after “brooding on the data” as Plummer recommends, I would rush to her to question the accuracy or plausibility of my interpretation. There would be a “Could I say this ...” or “ You know what I see here...” and she never ceased to amaze me with her mature and practical response.

I had been struggling with finding an end point, that “when do I put the full stop to mark the end of this report” stage that I am sure all inexperienced writers and researchers have felt. I began discussing the notion of the reflected self with M. I saw it so clearly in my data, but what fascinated me was that all my informants had a strong sense of self that did not embrace deficit as part of their identity. Outsiders – especially educators and therapists, even parents saw the ‘ LD’ and implied deficit as a core part of who they are. Yet this did not impact on the informants’ self – concept and identity to the point that it became part of how they saw themselves. All had high achieving siblings, yet still by comparison within the family they did not see themselves as “in deficit” – at least by the time I interviewed them, although all had felt that initially at school. I asked M. what she thought had happened- how come all this focus on what they could not do at school, all the focus on failure, intervention, even a formal

labeling or “diagnosis” that implies deficit or lack. She responded: we don’t know any other way - you can’t feel you’re missing something if you’ve never known what it’s like to have it – you don’t know what it’s like to be any different to who you are. I don’t know how K.’s brain works, so I don’t feel she’s better than me, just different.

This revealed for me the primary difference between my understanding of LD as an educator, a “labeler”, and M’s understanding of it as “the labeled”.

3.Helen's story:

I have dealt elsewhere with my initial dilemma over whether to include her in my research and what the impact would be on both her relationship with Michelle and her family's relationship with me through this process. However I had the privilege of their full support and so far we seem to have managed to keep the "researcher" out of the social relationship. I chose never to interview Helen at my home, in order to keep that the place for her relationship with Michelle. When I conducted one interview at her home, the initial one, her parents were at home but not present during the interview. Prior to that I had never visited on my own, so a visit to do the interview was in no way comparable to any of my other visits to their home. I also tried never to talk about anything that may be construed "research" when she was visiting our home or when she and Michelle were together. Both were however aware of the other's participation in the research. Obviously all research data, whether transcripts from interviews or audio journals was kept confidential. I never asked either of the girls if they ever discussed the research, the interviews or their audio journals.

Perhaps because of her close friendship with Michelle. and therefore by default her relationship with me as M.'s mother, Helen. may have been concerned about how confidential the data would remain. However I did not get the sense that she was being anything other than open and forthright in the interviews and in her audio journal. Ina addition to this she submitted a written reflection of her school years of her own volition. I felt this was an indication of her commitment to this research and to the "making known" all that she felt was relevant. This was an emotive reflection on being ADHD, including commentary on her own use of psych-stimulant medication and the experience of being judged as a result of this.

Background:

Helen is a happy, warm and vibrant young woman. She is the participant I know best, next to my own daughter, as she had been a close friend to Michelle for nearly 10 years when I first interviewed her. Helen is the younger of two children from an intact family unit. She has an older brother who is an academic achiever and who has leadership qualities. She was 'diagnosed' as having a learning disability in her first year of school, shortly after commencing grade 1. This was done through a process of multi-disciplinary assessment, including both a psychological assessment and a speech-language assessment. She was transferred from a mainstream junior primary school to a short-term remedial school in her first grade. She then spent the balance of the junior primary phase (just over 2 years) in the remedial school before returning to a mainstream school in grade 4, the beginning of the senior primary phase. While in the remedial school she continued to receive speech-language therapy, remedial support and occupational therapy.

Helen describes herself as hard-working, motivated, creative and fun. She is very close to her family. In her life away from school she is involved in her community church as well as the wider church organization. She has run a tuck shop for her youth group, acted as a camp counselor and during her school holidays worked as a teacher aide in a preschool.

What is clear is that however she sees herself, her ADHD is a significant part of her identity. This is an issue raised in all the methods of data collection: the interview data, her audio journal, even a collage she did to depict her identity. At the end of the data collection process she was asked to reflect back on her school career. She did this by submitting a 3 page essay that focuses on being ADHD, including attitudes of teachers and peers towards people with ADHD, and the issue of medication. There was little reference to scholastic difficulty. I believe this underscores the importance of reviewing the kind of support that is given to children with LD in schools, but will discuss this in the following chapter.

Helen speaks:

My earliest school memories are of preschool, a happy time as far as I can recall. *I used to like going into the imaginary place, that corner of the room where I could be alone. I loved reading the books or fantasizing, you know, dressing up, and playing games. I enjoyed craft work such as can also wood work. I enjoyed making something and then imagining that it was a car or train or anything I wanted it to be.*

Going into grade 1, the start of the junior primary phase of my education, was less than memorable. I had looked forward to this for so long. My older brother, whom I adored, was at the school. Many of my friends from preschool were going to be there. I recall the anticipation typical of many children who have been told for so long “when you go to big school, you will learn to read and write.” However it was a most frustrating time. *I didn’t really learn that much there. -I think they tried to teach us how to read there, and I just didn’t really get how to read.* There was all this focus on learning sounds or phonics and practicing words and I really tried, but I just couldn’t read. To be quite honest *I didn’t really learn that much that’s why nothing really sticks in my mind.* Anyway it seems that *that’s when they sent me to Ridge Remedial*, a school for learners with special educational needs. It seems the difficulty I had was identified early, and less than mid-way through my first year (grade 1) I was accepted and transferred to a short term remedial school. This whole process was one over which I felt I had no say or control. All I hoped was that the new school would be a better place for me. ³⁵

³⁵ Fortunately for H, her difficulties were identified early, and less than mid-way through her first year (grade 1) she had been accepted and transferred to a short term remedial school. This whole process was one over which she felt she had no say or control . She too does not personalize her first teachers, but refers to nameless , faceless “they” not being able to teach her to read and “ they” sending her to remedial school. This reveals her sense of powerlessness and lack of control. In all likelihood the decision to move her to remedial school would not have been made by the teachers but by her parents, in consultation with a number of professionals. The process for transfer from mainstream to remedial education at the time was

Due to poor progress and apparent difficulties in grade 1 I was referred for assessment and identified as a candidate for short-term remedial placement at Ridge Remedial. This school was approximately 25 Km. from my home. Despite the extra distance and traveling time to and from school, and despite having to make new friends, I did not experience this move as traumatic or difficult. It was *not that big a deal for me*, and *I liked Ridge, it was nice*. In fact now 10 years later as I reflect back on my school career I realize just what special place it was for me. *I have always found school difficult.. I suppose that was one of the many reasons I loved RR... I really enjoyed St. Francis College (mainstream school I attended from grade 4), but RR will always be the best.*

It was such a relief to be in a place where *everyone was like me, they all had problems* and I was no longer the odd one out. My time there was *fun, exciting*. I can recall even now 10 years later an entrepreneurship day we

one that required assessment by an educational psychologist at least, and usually a speech language pathologist and occupational therapist, as well as school reports and remedial assessment where relevant. The referring documents would then be scrutinized by the remedial school team, who after consultation with the class teacher and the therapists at the remedial school, would accept or reject a recommendation. The child would then usually move schools at the end of a year or at least at the end of a term.

Of all 4 of the participants who went to remedial school, she was the only one who went into a remedial school during her first year in grade 1. At the time this was unusual but it was starting to occur more often as the remedial facilities became better known and as parents too became aware of the support available for their children. This was the mid 1990's, when inclusive education was not policy in South Africa, and when the 14 Education departments that had existed prior to 1994 were being rationalized. A special task force called the national Commission on Special Needs in Education and Training was set up in 1996 by the new democratically elected government, to look at special education and learners with special educational needs (LSEN). The groundwork for what would, in 2001, become White Paper 6 on inclusive education was laid by this task force. However at the time of H's entry into grade 1 and subsequently remedial school (1996??) support for LSEN in mainstream school was minimal, and where resources were available (particularly financial) parents were advised to place their children with SEN into schools which could provide the necessary support such as remedial teaching, occupational therapy, speech-language therapy etc

had where learners were given money and had to use maths and numeracy skills to buy and sell small goods to and from each other. Perhaps this was where my interest in business and commerce started.

Although I recall the leaning and the friends and the fun, what I remembers most about my time at Ridge are the teachers. They were gifted in making *everything just seem to be fun – it didn't seem like anything was “äh, it's work again” ... they made everything so enjoyable – you would learn so much there.* This was so different to my previous school *where I didn't really learn that much.*

I remember specific strategies such as mnemonics that were taught to me by my teachers at Ridge; things like *our maths teacher taught us that anything times naught is naught and that's the rule that we've been taught. I don't know why it's just stuck in my head and I always remember that.* I don't remember anything other teachers taught me in my first school.

Although I rate my time at Ridge higher than any of my other school days, make no mistake we worked hard. *I can remember doing homework for hours on end, there was so much homework.³⁶ Our timed reading used to take ages to do and we had to do the spelling where we had to put our hand over it and copy it and cover it and it used to take ages.* We called

³⁶ Pressure to achieve and “close the gap” between potential and performance was great at the remedial school. In fact the acceptance criteria included the assumption that the learner would return to mainstream within a 2-3 year period. There were long-term remedial schools for those learners who were not considered ‘mainstreamable.’ However in Helen’s case she was considered a good candidate for short-term remedial support. In her favour was the age at which she entered the support system (still in her grade 1 year), the extent of the “deficit”/difficulties as described by teachers, and her ‘potential’ as defined by IQ assessment³⁶. In order to ‘remediate’ or ‘fix’ the deficits , however, it was necessary not only to keep pace with what would be considered the normal mainstream curriculum, but in addition to this to provide the necessary support to ‘close the gap.’ As a result the homework load was enormous. There was also the need to keep up with class work when during the school day a learner might leave the classroom to attend occupational therapy, speech-language therapy or visit the school psychologist.

this SACAWAC. Despite what would appear on the outside to be the drudgery of a school day that never seemed to end (*and I can remember coming home and just doing homework and homework and homework*) I accepted this because *I suppose that's all I really knew – I didn't know any other way so it didn't really make a difference.*

In addition to homework and school therapy support, *I also used to go to speech-language therapy in the afternoon. I always used to enjoy going there. After school I used to go to art club and played sport. I used to do running, cross country and I tried netball, but because of the distance of the school from my home I didn't do that much because I was in a lift club so then times were difficult if we all finished at different times.*

I loved Ridge, the remedial school, and rate my three years there as the best experience of school, and the best teachers, even though I left there 8 years ago.

It was also during this period at a remedial school that I was diagnosed as ADHD and started taking psycho-stimulant medication (Ritalin). *The older I get the more I start to see how many people have a warped view on ADD and Ritalin. Something that really really bugs me is people that think people that take Ritalin are all hyper. If someone's all enthusiastic and they have a lot of energy they say "I really think you should take Ritalin" or something but they don't actually know what Ritalin does and they don't actually use it in the right sense but it really bugs me. That's probably why I haven't told anyone that I take Ritalin – only Michelle knows and that's all the people that I actually want to know about it because they actually don't need to know that I take Ritalin. They'll just tease me and just make a big thing to talk about and joke about and I don't need someone to joke about that because I think it's a very serious thing for me. I think it helps a lot and I know the difference when I haven't taken it and I seem to not concentrate in class, it just helps so much for me and it's made such a difference in my life. Even sometimes when I've had to do drama or learn words for a play or anything like that, it just helps me learn the words*

more easily. I don't know what it is but it really really seems to help. I do have mixed feelings about taking it though. *I don't make irrational decisions on it, and am more confident. I don't feel 'fun' on it though,* not so spontaneous. I have a love-hater relationship with it I suppose. I have mixed feelings about how the medication affects my ability to perform tasks.

My early recollections and experiences are of taking the medication in an environment where many other learners were also taking it, where teachers had insight and knowledge about how the medication worked. This was when I was still at Ridge. The fact that my mother is a trained nurse may have influenced my parents' attitude towards the medication, which is very often controversial. I certainly have felt uncomfortable and even angry at times when teachers or peers *have preconceived ideas of how child* who is on Ritalin *will behave*. One of the teachers at the preschool where I do some part-time work as a teacher aide commented that a new child who was joining the school *will be a handful because he has ADD*. The comment was made before the child had entered the school, and was based purely on the teacher's preconceived notion of what the label "ADD" would mean. I have also experienced *teachers joking about it*, for example telling unruly children in the classroom that they should be on it, or suggesting that those who take the medication are on the path to drug dependency. I must say most of the time I am glad that I have not told anyone that I take Ritalin. When I first started taking it I only took the medication during school term times, and not on weekends or school holidays. However I now take it seven days per week. I remain committed to 'non-disclosure,' and only my family and closest friend know.

After 2 ½ years at remedial school I returned to mainstream. The move was *a bit hard*. Unfortunately due to a teacher falling ill and other unforeseen circumstances, I had 4 teachers in that year which was challenging. *Coming into a new school and then having 4 different teachers—your mind gets very confused which is quite difficult*. What was positive was that the return to mainstream was into grade 4, a stage during

which many new children come into a school who have previously been in junior primary school which only continue to grade 3. Therefore because *there were a lot of new children going into standard 2 (grade 4)- it was OK.*

However there was still a sense of loneliness, fear and feeling “Other”³⁷

I found it easier to go into Ridge though because everyone was like me – they all had problems. Going into a school where not everyone did have problems it was kind of difficult. No would understand what I was going through ; if I battled with something then they wouldn’t understand why I was battling with this because it was so easy to them.

Returning to mainstream was daunting, not because I felt ill- equipped to cope, but because I felt different. I felt *no would understand what I was going through.* This sense of alienation is a feeling I still experience (8 years later). *I always feel like it’s easier for them than it is for me-cos I always feel as though I’m battling and they’re fine with it. Aa lot of them do find it easier – and they all seem to understand questions fine-but then I won’t understand what the question is – they’ll find it a very easy questions and I’ll find it a very difficult question*

I recall teachers not being able to explain things in a way that I could understand: *I can remember one time when I was doing division and our teacher couldn’t explain it to us – wasn’t explaining it to us properly and then I came home and my dad taught me long division –and I dunno-sometimes I take a long time to grasp a certain concept – once I’ve grasped it then it’s fine – and I dunno the long division was just so much easier for me – and that mad quite a big difference—I still do long division-*

³⁷ It is the “exclusion in inclusion” expressed here that is common to all participants who spent time in a remedial school. Despite all the rhetoric around inclusive education, it is interesting that every participant who experienced a period of exclusion, a period of placement in a remedial facility, said they felt this was the first time they felt they were not alone

I just find it easier –she did eventually land up teaching me but I would never have understood it the way she had taught us

On returning to mainstream I continued to experience difficulties with the learning of other languages, difficulties which first manifested on the introduction of a second and then third language in the remedial school environment. *At Ridge we did Zulu for a while and I didn't like that,-I never enjoyed that. We also learnt Afrikaans which it confused me; I never really got what they were trying to say and I used to battle with my reading- it was very difficult to try and read.*

My difficulties with language learning were not confined to the second language.³⁸ *We had a really hard English test today,-it was about our set book. I didn't understand one bit about the questions and there was an article that you had to refer to and I didn't understand the article either. I found it really difficult and obviously because it was a test no one could help me.*

³⁸ This is consistent with what the definitions of LD say about specific difficulties with language based tasks. Even as she recalls these early difficulties there is reference to difficulties with language learning and difficulties with reading. Both are referred to in the definitions of LD and dyslexia cited in Chapter 2. The introduction of a second language in the junior primary phase was a compulsory part of the curriculum in South African schools. In English medium schools the second language was, at the time, Afrikaans³⁸. During the senior primary phase a third language was introduced. This, in government schools, was one of the indigenous African languages, most often the language common to the area. In Kwazulu-Natal this was isiZulu, the mother-tongue of more than XX % of the population of the province. Since the late 1990's this has changed, with a move towards mother –tongue instruction in the junior primary phase where possible. In some schools, particularly private schools, it is possible to select a language other than Afrikaans as a second language. It is also possible to apply for exemption from being examined in a second language, particularly where either a hearing loss or language learning disability exists. However such exemption is usually only granted after detailed motivation from teachers, a psychologist, and a speech-language therapist. In H's case this was done for the third language (isiZulu), but she continued with the second language (Afrikaans) throughout her schooling. However the compulsory second language requirement had a significant, negative impact on her final school leaving aggregate

I experience a very specific difficulty in the area of comprehension, one of the typical “deficits” in children with learning disabilities (Sternberg & Grigorenko, 2000:5). *I often don’t understand questions and when people try to explain them to me I still don’t understand them and I find that very annoying*

I have come to a “comfortable co-existence” with my learning difference. This is what I do know though: *Being LD you learn that things are going to take you longer than most people. I battle to say what I mean³⁹ and I have difficulty remembering past lessons e.g. content ; and need someone to re-teach me the same thing again.⁴⁰*

I find it frustrating that things take longer, but look for support and make use of extra lessons , as well as the time and spelling concessions allowed for tests and exams. However the act of requesting these concessions has meant a declaration of “otherness” that I was reluctant to make⁴¹.

I have also learnt to seek support from peers, and rely more on this than on teacher support. However despite this apparent self – acceptance, I reject any form of labeling. The label that bothers me most is the ADHD label, due to the association with medication and the stigma attached to this, that I hear reflected in the comment of others. The example mentioned above of the teacher anticipating a ‘difficult child’ at the preschool where I helped out during my holidays is just one of many that show stigma and judgment.

³⁹ a clear reference to word finding difficulty, which is discussed in the following chapter

⁴⁰ Possibly a reference to poor auditory recall

⁴¹ One other participant did not make the same requests for that very reason, but chose not to make use of the support systems allowed in order to continue to be perceived as “ the same” as the other learners.

4 Brian's story

Background

B. was in grade 7 and 13 years old at the time of the initial interview, and he was attending a remedial school, a school for learners with special educational needs (LSEN). By the time of the final interview he had progressed to high school and was in a mainstream school in grade 8. He has an older sister and comes from an intact and loving family. He is clearly close to his parents and refers to doing things and achieving *to make them proud*. He lives in a well maintained home in a quiet and up-market neighbourhood.

He seemed eager to participate in the research but during the interviews he revealed very little about himself. A comparison of the transcripts and analysis matrices for his interviews with those of the other participants reveals much shorter transcripts, frequent mono-syllabic and one-word answers, where it was more usual for the other participants to elaborate on responses spontaneously.

Brian is a serious young man who clearly takes his commitment to others as seriously as he does most other things in his life. He is shy and reticent when it comes to talking about his scholastic experiences. This is something not unique to the research process or to his interaction with me, the researcher. He has been uncommunicative at home too. In fact his participation in the research was endorsed by his parent who felt he needed to talk to someone and as he wasn't talking to them they hoped it would be me. To their credit they respected the confidentiality of the research process and never requested feedback regarding the content of the discussion in the interviews.

I begin B's story with this extract from my research journal, as it forms a backdrop to the story that follows. The story I present is B's story from the data, and not, I believe, B's REAL story.

I am really concerned about B's reticence- I'm not convinced that this (LD) really isn't an issue to him – just from demeanour, body behaviour, rubbing of eyes, breaking of eye contact., long staring out of the window before responding – there's still not enough trust between us for him to be completely open and its interesting because he's a child with whom I've had a therapeutic relationship and have observed in his school context over a long period of time. Despite his reticence in the interviews he ends his audio journal entries with comments like “ thank you very much” and “I hope you like this,” suggesting a desire to please me.

What was also interesting was his reluctance to describe himself and his initial usage of the two words “hyper’ and he doesn't like “teasing” – and only when probed and encouraged he mentioned good at sport. Once the tape was switched off and we were just talking about the forthcoming interview and the school holidays and whether he would be available, he mentioned that the family were going down the coast and then the spontaneously mentioned how he and his sister both love body boarding – they body board together – so their closeness is also not something that came up at all in the interview. He's an interesting child and I still don't have his real story

I've asked B to do a life map for me before our next visit...I really want to find other ways of tapping into his story.

Brian speaks:

I attended preschool where I formed friendships that have endured. I recall very little of preschool, other than the friends I made. *I made two friends that I still know today. Going into grade one was much harder and I got more homework, but I also got more friends..* I have already been to three schools: in grade 1 I was at Oaklands Primary, in Grade 2, 3 and 4 I was at St. James, and then grade 5,6 And 7 at Ridge Remedial till now⁴². I attended a government school for the first year of the junior primary phase of schooling and then moved to a private school for grades 2,3, and 4. My first years in junior primary school were noisy and bewildering, with *big noisy classes* being all that I recall from the two mainstream schools I have attended so far. *I didn't like such big classes.* At St James, the private school, the teachers were *too strict*, and we had *required to learn prayer books*, a task I found pressuring. It was *a nice school* though and *had two big fields*, something I do remember because *I enjoy sport* so much.⁴³

In grade 5 I was moved to a short term remedial facility, *Ridge Remedial, and spent three years there.* The move to remedial school was something that made my parents happy. It seemed to me like *the work was much easier there. I think it was better for me to go there because I had real difficulties.* Now that I'm in high school I feel that my time at Ridge Remedial school *actually helped me quite a lot.* I believe Ridge *fixed me.* *I don't know how though, maybe just by making me learn, making me get good marks* so I could see that I could do it. My time there was the best

⁴² B. moved into high school, which marked his return to mainstream, during the date collection process, between interviews 1 and 2. This was then his fourth school.

⁴³ He does not describe early experiences of scholastic failure but clearly the memories are painful. This is apparent in his limited responses to questions about this time that betray more than poor recall. His frequent responses "dunno" and "can't remember" in themselves do not suggest this but rather his body behaviour as he says these words- he breaks eye contact, swings his foot, fidgets in his chair and at one stage wipes his eyes but insists "dunno" and "can't remember".

time – I *easily rate it as 10/10* compared to the school I am at now, high school, where *its like 7/10*.

All my favourite teachers, Mr. B., Mrs. N, Miss. C and Mrs. C were all teachers from Ridge. I don't have any favourites from the other three schools I've been to. I think that what made them special was that they were understanding, if someone was not there to do a test they would cancel the test till that person came back. They didn't shout, they were patient and gave you more time to do things. The teachers were much nicer than other schools I've been to, they let us have art when we've finished all our work or if there's no work to do.

When I moved to Ridge *I made friends* again fairly easily on moving from mainstream, and as with my preschool friends I have maintained these friendships as I moved to my new high school⁴⁴.

I am currently in a mainstream high school where I have just completed my first year, grade 8. Again it was easy *making friends* when I moved. In the beginning *I stuck together with the three others who came from Ridge* when I did, *and then they started to get some friends and I started to get some friends and now all their friends and my friends are together and we stick with them in a big group.*

*School is hard now because there are more subjects, but I feel like I am coping*⁴⁵. I found the most significant change being the size of the class

⁴⁴ Despite his quiet and serious persona, he mentions friends and friendships first in his description of all phases of schooling. Clearly friends are important to him and he is a popular and sociable young man when with his peers. He has a large group of friends, some of whom share his history of remedial intervention. Their friendship stems from their familiarity with each other – they all attended a previous school together – rather than their shared learning difficulties/ differences.

⁴⁵ In the following extract from my research journal it is clear that this is not reflected in his marks, and therefore in terms of the criteria currently laid down by the school system he is “not coping”:

and the extra responsibility placed on learners. I moved from a school where homework was a large and stressful part of the day, to a school where teachers left responsibility for completion of homework to learners, and seldom *check* whether it had been done. I have recently started receiving extra lessons for maths, even though I feel I am making progress. *My maths mark has changed a lot and although I'm getting bad marks in my tests and all that, I'm finally getting there without going to extra maths or anything. I'm finally getting up to the stage where I can do the work now on my own.* I am going to extra maths because *my sister put my name down*, I don't feel like I want to or need to go. Maths is one of my favourite subjects, maths and technical drawing. I think *I can do the same as everyone in my class, just sometimes I'm a bit slower than them*, that's all. *I try and memorize my work for homework. That depends on how much work we've got though because if we've got no homework we still have to memorize for 20 minutes for each subject, what we've done in class.*

Phoned B. to confirm my interview with him this afternoon and he wasn't home but his mom needed to talk. She had just received his end of term school report and apparently it is very weak – mom extremely concerned as B. "doesn't talk" at home and parents are at a loss as to where to go from here and how to deal with his continued academic failure (he has apparently failed most subjects in this his first term in high school and his first term back in mainstream.)

Mrs. A really at the end of her tether. She mentioned that B. has a past history of depression and was monitored by a psychologist at the time (prior to his admission to Ridge). She seemed to need to speak, and spoke openly but at the time and due to the circumstances I felt uncomfortable butting in and saying "do you mind if I record this as data" – so how do I admit what was discussed? I did say to her that it sounds like she and I need to talk – however there are issues here that are best dealt with by a psychologist.

Yet again though I was left feeling desperate for a child and a family that is floundering in the desire to do what is best for their child yet not knowing where to get the support. This again is a point where the school system should be serving the needs of the learner and his family and yet it is the schools system that is failing abysmally

The subject I enjoy most now is *natural sciences – you can study locusts, spiders, plants, animal life*. The one I enjoy the least Zulu, *it's a hard subject*. The Zulu teacher says *I am getting there but I don't think so because I'm still getting low marks for Zulu*⁴⁶

One thing that is difficult to get used to now I'm back in mainstream, is the bigger classes. At Ridge there were 16 people in my class, *now there's 36*. With more people in the class now the classroom has become a much noisier environment. This makes it *hard to concentrate because in class they always make noises*.

I have recently gone back on to medication to help me to focus or concentrate. It does *help me focus on the teacher*. I was on Ritalin previously, for approximately 6 months, but had a period where I did not take any medication at the end of grade 7 because *we weren't doing much work then*. I have not told my friends or teachers that I am taking medication for concentration *because it is none of their business*".⁴⁷. In fact *I've never spoken to any of my friends about my learning or what was hard for me, even the others who were with me at Ridge. I'm not that kind of boy who likes people teasing him*. I have had people before *tease me and make some comments about things*, especially taking Ritalin. Before when people knew *I was taking it the teased me about taking drugs*⁴⁸.

⁴⁶ What is interesting about this is that according to B.'s school report the subject he is consistently failing to achieve in, the subject where he has his weakest mark at 45%, is the one he reports enjoying the most. Conversely, Zulu, which he says is the one he enjoys the least, is one of his stronger subjects and his second highest mark.

⁴⁷ The reluctance to disclose this information is discussed further in Chapter 5, as it was a common theme from all informants

⁴⁸ Although he previously denied being teased he mentioned when describing himself that he was not the kind of person who likes being teased and admitted that he had experienced teasing when being on the medication before. Again it is interesting to note that this occurred in an environment where there was much awareness – both on the part of the teacher and the learners- about the use of medication for concentration difficulties and where a significant number of learners (get stats???) have at some stage been on medication. One might assume this would make learners more sensitive to peers

I feel I am calmer and able to cope with a larger volume of work when I take my tablets. *I don't know how it works but it helps me to focus on the teacher.* Although I understand that I have *a busy mind* and therefore take medication, the noise levels in the classroom make it difficult for me to concentrate, so it is not only because of me and my busy mind that I can't concentrate.

Sport has featured largely in my school life thus far. I love sport *and play cricket and rugby; I am good* at these sports and play for my school teams. I also enjoy water sports including *swimming and body boarding* and *I do judo* outside of school. I hope to *also play water polo* in high school.

My happiest memory of school is when our house won the swimming gala. My worst memory of school is also related to sport, and that is when my house lost the Athletics day. On both of these occasions I was just part of a much bigger team effort, and the success and failure were not on a personal level, yet these are the things I remember as my “best” and “worst” memories of school so far. I participated in an inter-school cross-country event, and although *I knew I was going to be slow and I was lazy, at least I made it and finished finally. My parents said at least I made it. I am hoping to run faster now* in the net cross-country event so *I can make my parents more proud*⁴⁹.

⁴⁹ This notion of achieving not for his own sake but to please others in one I return to in the following chapter. It is one I found in other participants too and suggest that their end goal is to please others and that their motivation comes from that desire.

5.Sarah's story

Sarah is one of the participants I did not know prior to the research interviews. However she was open and eager to participate in the research. The initial interview took place at her home on a weekday afternoon. In my research journal I wrote immediately after the initial interview:

I am aware that she knows I am the mother of a peer and therefore may not be completely comfortable through the interview at this stage. Issues around trust have not been explored beyond the initial assurances of confidentiality. However during the interview process I felt she held nothing back, and responded and described her history of LD as frankly as she could. She seemed to say less in her audio journals, which was interesting. The journals for some of the participants were more confidential and their entries were at times very emotional. However Sarah seemed constrained in hers, and anxious that what she had to say was relevant, frequently asking – *is this what you want to know?*

Sarah is also the only participant who stayed in mainstream education but moved from government to a private school. She received speech language therapy and remedial therapy after school.

Background:

Sarah is the younger of two daughters for an intact nuclear family. Her early childhood was spent in a small rural community. Shortly after she started formal schooling the family moved to a large, middle class suburb where there were five primary schools within a 10 km radius of her home. Two of the top performing⁵⁰ high schools were within walking distance of her home.

Sarah was the only informant in this study who never spent any time in either a remedial class, unit or school. She first presented with scholastic difficulty in her junior primary phase, but received remedial teaching and speech-language therapy outside of school hours on a private basis. Her parents elected to send her to a private school during the senior primary phase of her schooling, ostensibly because of the smaller classes. This was not an uncommon decision for parents whose children were failing to cope in the classroom and who had the resources to afford private schooling. The much lower teacher: learner ratio in the private schools at the time meant that parents felt their children would get more one-on-one attention from the teachers.

Her move was explained more as a need for “remedial” and therefore a recognition that a choice had to be made based on her scholastic performance. Yet the choice was still to a mainstream, albeit private, school that offered additional therapies as on a private basis on the school premises. Sarah continued to receive private remedial teaching through the first years of her senior primary schooling. She also dropped the third language requirement (this is discussed further in the following chapter).

⁵⁰ This is reference to the number of A class matriculants in the school annually; both schools regularly produced at least one of the top 20 students in the province in the school –leaving (matriculation) exams

Sarah speaks:

From what I can recall of my early history, it was uneventful. I attended preschool in a small semi-rural community – *there were about 180 – 80 houses*, and it was as I recall a happy time. I attended a small community school for the first two years of school, grades 1 and 2 *There were about fifteen in the class– it was a very very small school and* most of my friends were the same friends I had had at preschool. In preschool and grade 1 I felt no different to the other children and *I wasn't teased* or anything like that then. It was during the second year there that I *found I wouldn't be able to read properly. There were things that I couldn't do as well as the other children, but* this was *not really a problem*. I didn't need extra lessons or extra help at that stage. Maybe this was because I was in such a small class. *I didn't really start going to remedial in primary school – I really started* after we moved and I went to *grade 3*.

In my third year, grade 3, the family moved to a large suburb which had four government junior primary schools within a 15 Km radius as well as two small private primary schools. I attended grade 3 at one of the better known government schools, some 2 Km from my home. It was at this point that it became apparent that I may have a learning disability. *My mom kind of found out that I had a bit of a problem with reading – mainly with reading and English – not really in maths yet but- just I wouldn't be able to read properly. I also saw myself being worse at learning and stuff outside of sport than the other children. I wasn't good at any of those sort of things.*⁵¹

⁵¹ This tentative reference to “a little bit of a problem” that her mother “sort of found out” suggests that at least at that stage this was not understood to be a big issue or fully accepted as part of her identity. There is no sense that “I am LD and therefore LD is something that constitutes part of me,” even as she reflects back on the early identification of “a problem.”

This early awareness that she was “worse at learning” was not related to any on specific incident and she does not report the humiliation related to

At the end of that year, I had to move to a senior primary school for grade 4 onward. My mother saw this as an opportunity to move me to a private school – it was going to be a time of change for me anyway, so a move was inevitable. *I actually don't know* how the final choice was made to go to St Francis College. *I think its just that St Francis College is more a remedial school.*⁵² The choice of school was not only motivated by my learning difficulties but also the need for smaller classes, the ethos of the private school chosen which at the time promoted an ethos of “nurturing the whole child.”

Another factor affecting the decision was that *I think my mom thought that the government schools might be changing a lot and she didn't want that change to affect us , so she moved my sister first to St Francis and then she moved me*⁵³. I do remember the biggest changes for me with that move

specific incidents that both H. and M. recall. In Gidden's (REF) terms, her actions or behaviour did not fit the structure, or organized actions and behaviour patterns of those around her, particularly in the specific context of the classroom. S. is one of the participants who never experiences the sense of belonging that all the other participants did when they moved to remedial classes or schools. For them the structure changed and it was a change that was instigated by the different actions of those around them – a different society in a sense where there was enough of this different or alternate behaviour to generate a changed structure.

⁵² There was the perception that St Francis College was more sympathetic to learners with special educational needs, not only because of the smaller classes but because of the offering of additional therapies such as speech language therapy, remedial therapy and occupational therapy , offered by private practitioners but during the school day and on the school premises. It was also, at the time , a school that took many of the learners who had previously been in a short term remedial facility due to their special needs. As a result parents elected to make the financial sacrifices necessary to have their children in an environment where there were smaller classes than the state mainstream schools. The private schools on the whole had an enormous focus on academic achievement and this particular one at the time (mid 1990's) set itself apart as the school that would identify and nurture strengths in all its learners, not just those who were academic achievers.

⁵³ At the same time, immediately post the historic elections of 1994 in South Africa, the new and first fully democratically elected government

were that the classes were a bit smaller. It wasn't really a big move for me because I still had friends. When I came to St Francis College I had a lot of friends as well there, - so there wasn't such a big change for me to adjust to. The move was initially not a happy one for me as this was my third school in four years. It was here that the teasing started, not only about my learning- not even about my learning- more about other stuff in my life.⁵⁴

Both my “worst year” and my “best year” occurred there. *Standard 4 (grade 6) was the worst year – really the worst year :-it was a very very bad year for me. I was going through a friend situation and I would tell some friends personal stuff and then they would go and tell other people. There was one guy in particular who would sit in class and wouldn't stop irritating me and keep on teasing me and it really got to me , and it got to my work as well. I just changed friends totally and then in std 6 (grade 8)I changed again. The other years weren't that bad, they were fine. I just got over it because lots of people go through that stage in their life but standard 4 would stick out as the worst year and standard 5 was I think the best year in the senior primary because I had a good group of friends. I*

began the process of redressing inequities of the previous years, including the enormous inequalities in the education system. As a result of the opening of previously “White” schools to all race groups, and shifts in learner numbers and teacher –learner ratios, many middle class parents from all race groups began looking to private education as a necessity rather than a luxury for the elite. There was a period of instability, the introduction of new curricula, negative publicity around some of the changes that were being introduced (both curricular and in terms of school rules and regulations) and parents who previously would have considered private schooling a luxury for the elite were now beginning to look to private schools as a necessity they would make other sacrifices to afford.

⁵⁴ That this teasing did not appear to be as a result of her learning differences is significant in that it again is a different experience to A., H. and M., all of whom were teased about their learning differences. This again reveals how the experiences that are seen as worthy of discussion by these children were not around scholastic difficulty, or around the specifics of their “LD” as defined objectively. Rather the experiences that stand out for them are experiences around friendship and trust and betrayal.

*had a good group of friends so I knew they wouldn't really go and tell other people "personal things, who would not betray me."*⁵⁵

I know I have a bit of a problem .I do see that I'm a bit slower at getting things than the other children – there are things that I've got – I've matured. I see it as a problem in me... and that some aspects will still be with me for a long time. I have made changes because of it, I stopped doing isiZulu (a third language,) cos I just found that was too much of a workload on me:

I recall bad experiences with teachers *who couldn't control the class* and my worst teacher was *one who was very sour*. Positive experiences resulted from teachers who were *very caring and very nice*. The accolade of the best teacher ever must go *to a Mr. B – I think he was like the best teacher I've ever had – he related well to the class, was there for them, was supportive and had a sense of humour. He was a nice person. I think he was a good educator –but he could relate to the children really well – he could chat to you and play around with the kids. He was there for the pupils*. The teacher can make me enjoy or hate a subject.⁵⁶

I enjoy the subjects I can achieve in and particularly *dislike art*. I used to *hate English* through primary school and early high school but now in grade 9 (time of interview), I find it more enjoyable. What has happened in

⁵⁵ S. is the only one of the five informants who did not spend time in a remedial school or remedial unit. I posit that this may be why her recollection about teasing is not linked in any way to her learning disability. One positive aspect of her continuing in a mainstream, albeit private, school is that she is able to continue to minimize her learning difference

⁵⁶ As with all other informants, S. maintained teachers as being responsible for both positive and negative experiences. She links teaching and teachers to her enjoyment of a subject – she disliked history until she had a teacher who could control the class. She now she enjoys the subject even though she finds the workload heavy, and refers directly to her enjoyment as being due to the teacher's ability to control the class . This is similar to M.'s comment and H.'s reference to

the interim is that my marks have improved, which may be either the cause or the result of my new enthusiasm for the subject. I think though it is because *all my teachers I've had for english were fine*. I used to love drama and *this year as well I don't like going to drama – if drama comes around I dread it because I can't stand it*. In std 6 (grade 8) my history teacher *didn't really get a lot of work done because she couldn't really control the class so I didn't really like history*. Then in std. 7 I had another teacher for history who *she was really good, she could control the class and we've been doing a lot of work so I do prefer history now*.

When I require additional support if I don't understand something in class I don't go to the teacher. *If I can't do it then I'll go to my dad or to my mom sometimes. If I sort of understand then I'll ask my mom or my sister. I'll go to someone in my family or maybe I'll ask one of my friends if they understand it. If none of them understand I'll go to the teacher and ask, and I'll persist if they don't explain it to me and I still don't understand I'll go "Please explain it to me again." Then she'll have to explain it to me until I understand it*.

I had remedial therapy and for 6 years through junior and senior primary school which *helped a lot* even though I *didn't really like it* because of the extra work. Anyway my *marks have improved greatly* so the remedial was worth it. My biggest criticism of the remedial teaching was that it was time consuming, as it occurred over and above the normal school day. I had to do all this additional homework. In fact the workload was the reason I decided to discontinue isiZulu in high school, *I just found that was too much of a workload on me* and it was one of my *weakest subjects, so I stopped*.

Through primary school I think *most of the teachers knew who was in remedial and who had a problem and they would help you along*. In high school they *don't really help you along*. Maybe they *don't actually notice* if you're having difficulty. It was easier to ask in primary school because *you don't really do as much work in primary school so the teachers could*

see if you understood and they would help you. All teachers were aware of my need for extra support and sympathetic to my learning needs.

Now I'm in high school and I know *if you don't understand you must just ask and they do help, but they don't help you* like a remedial teacher would. The teachers are either unaware of my history or unable to help. I don't feel as though they make any special effort to help me more than anyone else in my class. My main concern now is the pace of work, I really wish teachers would *help a little bit more and go a little bit slower maybe.*

I would describe my LD as being intrinsic *.In a way I see it as a problem in me. I understand it as I have a little bit of a learning problem . I do see that I'm a bit slower at getting things than the other children. There are things that I've got better at as I've matured but other things I think they will still be with me for a long time. I* accept this as something that will not disappear, despite progress. *I don't really see it as a huge issue; it is a big issue but it is not a huge issue. I don't think my friends really care if you have a learning problem , they really don't see it at all.*

6. Andrew's story

Background:

Andrew lives in an intact, nuclear family and attends a private school. At the time of the interview he was in grade 8. He repeated a grade in the primary phase of his schooling and attended a remedial unit for three years. He was moved from his junior primary school to a remedial unit in a mainstream school in the third grade, after presenting with scholastic difficulty. Assessment revealed a language learning disability. He still has difficulty with language tasks, particularly the second language requirement. Orally he presents with word retrieval difficulties that result in speech being nonfluent, as well as syllable deletion and transposition in some polysyllabic words. Although he spoke freely and in great detail during the interviews, he is the only informant who presented with speech and oral language that was, from my point of view as a speech-language therapist, disordered. A perusal of the verbatim transcripts reveals the false starts, interjections and ellipsis, as illustrated below:

False starts and interjections:

Ja – I can remember—I can remember a little bit – just um- I can --- things that stood out –like—I never used to know – I never used to know then like- cos I was small – how to tie my shoelaces----

I – I would- I would swim a lot in the summer and I'd – I really just – at home –I eat a lot when I'm at home – (laughs)

Ja-I log into the computer – and TV I just - mainly TV I leave for the weekends –I don't do a lot of TV during the week – unless there's a good movie on—um -ja- and I usually –not often but – when like this term there's no sport I roller blade – I like roller blading – ja – usually in my afternoons I just relax and do nothing leave my homework to do in the night time – afternoons I find something to do

Word finding:

No I read um—what you call it – ja- I read the Bible and if we have to read like an Afrikaans book or an English book I'd read it and then when they tell us in English to go and get books from the library and then I get one and it would just lie in my bag and I'd never read it

Andrew enjoys outdoor pursuits, and plays a lot of sport including cricket, swimming and rugby. He has excelled in rugby, being selected for the provincial schools team, and particularly enjoys rock climbing. He is close to his mother and his older brother.

The following two entries from my research journal reveal my first impressions of him:

He seems to be a serious young man, quite passive and at this stage not showing much emotion. I also find speech tends to become less intelligible at times – not due to articulation or phonological problems but incomplete sentences, false starts, and voice getting quieter at times: I am tempted to say “swallows words”- whatever that may mean. This is particularly noticeable on polysyllabic words

Later, when transcribing the data I wrote this:

The one who has been the biggest surprise is A. – the other males, who are younger, have given little more than commentary on their current school days and even those reflect only a fleeting acknowledgment of any scholastic difficulty. I certainly am not implying that I expected the kids to dwell on this aspect, but it is interesting that A., even in his first interview and first audio diary entries, bares his soul in a way that I find disconcerting. When I was transcribing one of his audio journal entries about writing an essay and he commented how speaking to a tape recorder was what he preferred and he wished he could submit his work this way, I actually wept – the tears flowed and I feel myself welling up even now writing about it. It was the excitement in his voice that said so much – the

impression was that he could do anything as long as he could do it orally. The difficulty and drudgery of written tasks was removed. He comments I another entry how he can sit down to write an essay and he feels 'blank,' he describes 'a puff of smoke' in his head that leaves him unable to think of anything to write. I never expected the comments of a relative stranger to have such an emotional impact on me.

Andrew speaks

My recollection of the preschool years and experiences during that time are happy. I *enjoyed* this time. I used to have friends who enjoyed the fantasy play like I did. One of the highlights of preschool, one of the few memories I have of that time, was we a *once we put on this concert that had something about dinosaurs* and we got to dress up- I enjoyed that.

I do however remember there being some things I couldn't do that others in my group could do. One thing in particular stands out : *I never used to know then because I was small, how to tie my shoelaces, and there was this bully and he always used to undo my shoelaces just because I never knew how to tie them, just to tease me. I suppose your enemies are gonna want to tease you and stuff but I don't really mind about them. Your whole schooling career you're always going to have them so its just something to just try and ignore.*

In the beginning of my school years I really never liked going to school. I never really liked the environment, but since I've been getting older and having a better understanding of work and things its been better. Another big thing has been making more friends and that's why I've been enjoying it more. I enjoy it more as I get older.

In grade one and grade two I wasn't really aware that there was a problem with the way I was coping but *my parents saw it, and there was a lot of meetings with the teacher and they decided I needed to move schools; they*

discussed it quite a bit before I moved. Then in grade three I moved from my primary school to Pineslopes Primary because there was a remedial unit there and I needed remedial help. Also it was better teaching and I liked the teaching better there. Whenever you asked for help you knew all the teachers would just give you the help so with every class every teacher was there for me, to help me.

I did have to repeat a year there though. When my mother told me I had to repeat the year I was quite sad. I understood the reason to be because I never finished all my work in one year and I worked slowly. I never really wanted to repeat but I had to because we were planning to put me into St Francis College in grade 4; I wanted to go to St Francis College. As it happened they told me to stay back and do 2 years in grade 4 at Pineslopes and I never really wanted to but I did. I only went to St Francis in grade 5. If I hadn't got into St Francis College I was gonna go to KPS, which had much bigger classes so it was better that I got into St Francis College.

Apart from really good teachers who were very helpful, at Pineslopes we never did a second language. Since I've done Afrikaans it's always been harder for me so it was good not to have to do it. Other subjects have always been hard for me too: maths especially. English has been all right but just Afrikaans and maths have been the worst.

I don't really have any worst experiences or memories of school. I suppose even though there's never really been a worst there are those things that upset you like going to school and knowing you have your enemies that are gonna want to tease you and stuff. I don't really mind about them, your whole schooling career you're always going to have them so it's just something I just try and ignore. You know you will always get teased your whole life so it's best to try and ignore it.

I was, and am still, very happy at St Francis College. We have such fun and I've made the best friends at here -it's the best friendliest school I've

known. We had a medieval feast which was really fun. Another thing about St Francis is the teachers are really understanding and the work has been mostly fun and enjoyable. If its boring they try to do something fun with our work and make it more enjoyable. It's a better school than any other school that I've been to.

When it comes to class work, I seem to enjoy the subjects if the teacher teaches me well and I understand what she's teaching me, no matter what the subject is, if I understand what they are trying to teach me then I enjoy that subject. I enjoy that subject very much because I understand what I have to do and -I can get on with it. If they get the right message across then I understand and then I know what to do. If there's a teacher that doesn't explain the work in the way that I can understand it, then I don't enjoy doing that work because even when I ask the teacher I don't really understand what to do. I'm sure if am taught something the way I like it I would get 80% or a high mark which would be good for me. Basically what I'm trying to say is if a teacher teaches in a way that I can relate to then I won't have any trouble I getting on with my work

I haven't thought about what subjects I want to chose for matric⁵⁷ yet, I only choose at the end of next year. I'm wanting to be a B Economics- B Economist . Since I started BE [business economics] last year in grade 7 I have liked it. At first I thought it was the teacher but I really enjoy the business world and dealing with like people and money and stuff about business. This year again I am enjoying it so I know it's the subject and not just the teacher that is making me enjoy it. I'll definitely chose with English, I have to anyway but its easy which makes me enjoy it more even though there's a lot of reading. I'll also do science because the practical is fun and its not such a hard learning subject if you understand what they're talking about. I don't think I'll go for art because that's too hard and I'm definitely not choosing history and I won't choose maths – well if

⁵⁷ It was a requirement at the time that at the end of grade 9 learners select at least 6 subjects to continue with through grade 10, 11 and 12 or to matriculation level. At least two languages were compulsory, one as mother tongue, and then various combination so of arts and or sciences depending largely on school resources.

I pass maths I'll probably have to go for it but if you fail maths you are not allowed to take it so I don't know. I'll have to see how next year goes.

Other problems I have are with Afrikaans, which I really don't understand even though I've tried to learn it. I've also tried Zulu and I don't understand, so I really just can't catch on in that language. It's also a bit of the teacher this year; I don't like her but last year I liked the teacher but I still couldn't do it. Maths, well I did like maths but I've actually been rather too lazy to do my work. As my mother says maths is a learning subject and you practice it every day. I'm lazy and I don't really listen in class and stuff and I don't know why I'm like that in that subject—it's just something I don't like. History is just such a big pile of learning and so much information. I can't handle that amount of information, it's just too much for me and I can't learn.

I've always been a slow worker and I'm always going to work slowly so I accept that. I think repeating that year in grade 4 was better for me to get that extra work in and to move on from there. There are things that I know will always be with me, things like my memory problem. I have a short term memory problem and it's quite irritating. It means I get taught in class or I get told or get something explained to me and then I come home and then a day or two later or maybe an hour – it depends how well I was listening at the time- I would have forgotten most of that, not all of it but most of it. I ask my friends, "hey what did that teacher say again," and "oh what did that friend say again," and my friends start to get quite irritated with me at times.

I had to do an art essay and I handed it in late and lost marks because I really found it so difficult to think of something to write. For me to write an essay like that doesn't excite me, but talking into a tape recorder is much better for me: I'd rather do an essay by explaining it on a tape recorder and hand in my tape in the teacher the next day. I hate writing, I'd rather type or I'd rather talk. I always like the teachers who say to me at school you're allowed to type work out. I do not like sitting and just

writing because firstly my handwriting is not good and secondly its boring; it doesn't excite me just sitting there and writing. When I sit there and write, fully fully fully concentrating, no noise around me, like I'm in a black square black, a room on my own, just sitting and concentrate fully, then I've got clear ideas coming into my head. If there is noise around I cant work, its just too distracting for me. In a classroom I'm not going to work if there's noise, I m going to sit there and talk with everyone else, but if everyone's sitting quietly working then I'll sit working because I need quietness to work. If its like group work then I can work with everyone talking because then I get everyone's ideas and stuff but otherwise I need to have quietness to do my work. If I get distracted on an essay and I've got my ideas in my head, I try to write fast because I don't want to lose my idea. Even though I've written a mind map out, sometimes I have even more ideas in my head so I just want to write and write and write. If someone walks in my room and asks me something and I get distracted then it all just goes and then I have to stop and think about for 5 minutes until I remember what I was on about and I get what I was trying to write. I forget forget things quite quickly. I hate being distracted at school. I like to work and then only once I've finished my work then I'll talk to the people. I'll talk to them if the teacher allows us to talk, but I'm not selfish I won't distract them if I'm finished , only if they're finished too.

I was on Ritalin even in junior primary, before I moved to Pineslopes Primary. When I got to Pineslopes though there was a whole group of people who took it and they had like a separate place where you had to take the Ritalin, so it wasn't really a big deal back then. I've never really had anyone say anything because I usually just take it at home. I don't talk about it or anything and no one knows and so it's fine, so I've not really experienced being teased about it or anything

I prefer to work at home and do homework because I always know I have a mother behind me to help. I do rely on her help but I realize that's not always a good thing because you've got to learn for later on in your life when you're not always going to have someone to be there for you to help

you. I am not always motivated but I will sit there and do the work that I really can get on with and I enjoy with it, but if its something like Afrikaans I'm just too lazy and I just get my mother to come and help me. I'm usually quite disciplined and I just get on and do the work, but sometimes I will just mess around the whole day because I noticed the teachers don't pick it up. Only a few teachers check in high school I've got so much English homework to do tonight and I have to hand it in tomorrow but I don't feel like doing it because its not something that excites me its not something what I want to be sitting and doing – its not something I really want to be sitting and doing but I have to o it because if I don't my English teacher is going to give me a Monday afternoon detention-so I have to sit and do it now

I like doing most of my work and homework at home – not only because I'm at home and by myself and can concentrate – I can close my door and lock myself in my room and then jus concentrate and then be able to just work nonstop because then if I do get stuck and do have a problem then I can ask one of my family – and they know how to help me in the way that I need to be helped – so they can like show me the problem and I can –um – carry on and go on with y homework – not like at school when the teacher sometimes can't help me the way I need to be helped – so that's why I prefer to have lots of homework – not like in the way – not every child likes lots of homework cos I don't but I d rather have the work and then get explained like it would be explained to me properly if I get stuck but I do like to play and like go to do sports and stuff in the afternoon –I stay up quite late in the night doing a lot of homework

Um- anything I don't like –um-some really stupid people in my class – like they just - they in high school now and they still act like they in grade one – sometimes they make you so mad you cant get on with your work and---um ---I don't like –um---I don't know because I do enjoy going to school and being with my friends and stuff – its much better than sitting at home all by yourself

PART THREE: The perception

*being the insight,
discernment,
reading,
observation,
view,
slant,
opinion,
experience*

in which I change the depth of field in the photograph

CHAPTER FIVE

DATA ANALYSIS: Interpreting the picture

In Chapter Four I presented my data in storied form. Five informants recounted their experiences of learning disability, and these reported experiences revealed how they understand or interpret their “condition.” These stories represent *their* reality, their *subjective* knowledge of LD. Through the telling of their stories they revealed both “the self- as-knower” or experiencing subject (James, 1990, cited in Leary & Tangney, 2003) and “the-self-as-known” or beliefs about themselves (Leary & Tangney, 2003:7). It is the former that dominates the discussion that follows.

In this chapter I attempt to answer the first critical question: What are the lived experiences of children with learning disability? I do this by presenting the primary themes from the stories which precede this chapter. It is these themes which I hope will throw a different light on how educators understand LD, by revealing how those who experience the LD understand it. The primary division of themes, which are all around the experience of LD, is not surprising. Given that LD is by definition a classroom-based or academic problem (Kavale & Forness, 2000, Ratner & Harris, 1994, Sternberg & Grigorenko, 2000, Thomas, 2000), the experiences recounted by my informants centred predominantly around school, classroom and learning. These are depicted in the diagram overleaf:

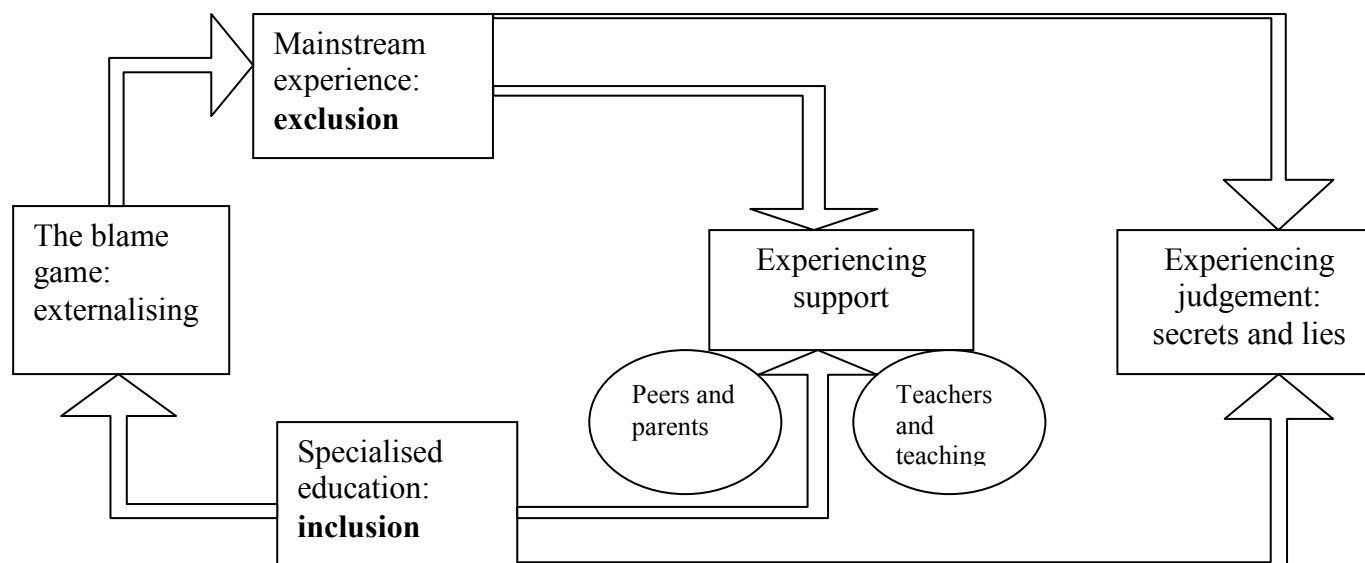


Figure 5: Diagrammatic representation of themes

Firstly I discuss two broad themes which I refer to as the school experiences. These relate directly to the curriculum and classroom performance, and are the **mainstream experience** and the **specialized (remedial) education experience**. I discuss this in the context of South African education policy around inclusive education. The philosophy behind inclusive education is that in embracing diversity, in including children who are different, be it due to physical or learning disability, they are not “Othered.” My argument is that the very inclusion of children with LD in fact is what makes them feel “Other.” By “Other” I mean a difference in their classroom performance, a sense of inadequacy or being incapable. I argue that it is only when experiencing specialized educational placement, with a group of children who share their LD, that they begin to feel that they are in fact not less than or inadequate in any way by virtue of their shared experiences. This assumption therefore leads to what I refer to as exclusion in inclusion.⁵⁸ By this I mean those experiences that set the informants apart from their peers, those experiences that either make them feel excluded, alien, less than, or isolated. I discuss this further below.

Linked to experiences both in mainstream and specialized education is the issue of support. Riddick (1996) describes the need for practical and emotional support expressed by her participants. I discuss this as I refer to **experiencing support** from two quarters: teachers and teaching and peers and parents. I explore the matter of social success that was highlighted by each informant. Friends and friendships featured prominently in their narratives, which was contrary to expectations given in the literature which details the poor social skills in children with LD (Fujiki et al., 2001, Kavale & Forness, 1996, Settle & Milich, 1999).

Another dominant theme is linked to school, relationships and society in general, and that is **experiencing judgment**. I have chosen to discuss this separately as I believe the strength of data generated warrants this.

⁵⁸ For this I credit Nyna Amin and Sbu Radebe, two of my doctoral cohort, who coined this term as we discussed my data.

However the experience of judgment and what I refer to as “secrets and lies” occurs both at school and extends outside the school context.

The final theme I discuss is what I refer to as “**the blame game**.” By this I suggest that my informants explain scholastic difficulty as the result of some external environmental condition or poor teaching, rather than some intrinsic weakness or deficit in themselves. However this only appears in the narratives after their experience in specialized or remedial education, after they have received remedial intervention.

In the final part of this chapter I show how my informants interpret and understand their condition, in other words the self-analysis that occurs through their experiences. It is this new, or at the very least, expanded understanding of LD that I believe supports my thesis.

1.The school experience

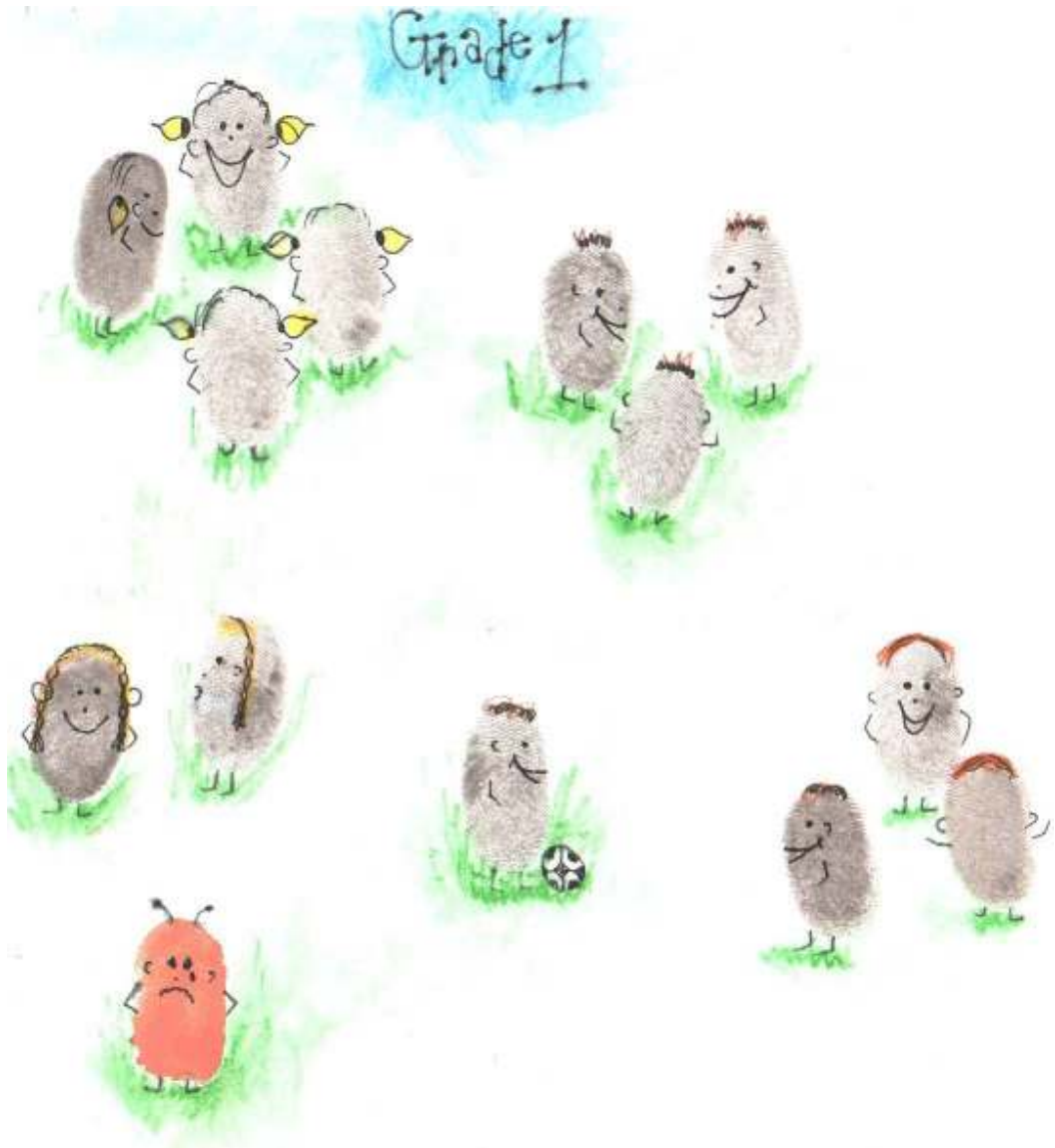


Figure 6: Thumb print submitted by an informant to show her experience of Grade 1: she is the "sore thumb" in the bottom left

The thumb print picture above was submitted by one of my informants quite spontaneously, after we had completed our first interview. She said it would tell me everything I needed to know about her early school experiences. She was in grade 10 when she completed the above, and I have chosen to include this piece of data as I believe it says so much more than I can. It reflects so eloquently the experience of isolation (being alone, in the corner, unhappy) and difference (the colour) that was typical of all my

informants' early school experience. Bear et al. (1998) suggest that despite the recognition of their LD and the classroom difficulties, children up to the end of the junior primary phase tend to look for and highlight the positive, and even suggest classroom performance is not a problem. Although I did not interview my informants during this phase, retrospectively they suggest this was in fact the worst and most difficult phase. For all of them by the end of the third grade they were already identified or diagnosed as having LD and requiring remedial support or specialized placement.

For the purposes of this discussion I have chosen to separate the informants' experiences in mainstream and specialized education. I believe the differences in these experiences add another dimension to the inclusive education debate. At a time when South African education policy supports inclusive education (DOE, 2001), I believe the experiences shared by my informants suggest at the very least a re-evaluation of what really is in the best interests of the child. I begin this discussion by highlighting the experiences of mainstream education: the experience of failure, humiliation, alienation/isolation and the growing awareness of being "Other," usually perceived as lacking or "in deficit." Low self esteem is intertwined with all of the above. I believe this low self esteem relates to feelings of marginalization and alienation that are directly linked to the experience of being different –an experience that was common to all of my informants when they were in a mainstream environment. I believe this sense of exclusion is one that inclusive education policy does not consider sufficiently. M. speaks about being punished for being unable to complete tasks in the allocated time. This loss of "play-time" and time to socialize and be away from the academic pressures of the classroom made her feel not only marginalized but judged, and that her behaviour was "bad." H., A. and B. all recount experiencing marginalization in their early years. It is this that I call "exclusion in inclusion."

1.1. Mainstream education: Experiencing exclusion in inclusion

For all my informants the first indication of a learning difference or what would later be labeled “learning disability” came in the junior primary phase (grades 1-3). All reported happy memories and positive experiences prior to this. All reported their first experiences of failure to measure up or achieve and the subsequent meetings between teachers and parents, as coming during this phase of their schooling. For both H. and M., this came in their very first year – their experiences in grade 1 were of failure, a discussion I take up below in section 1.1.1, as well as punishment and disappointment:

M.:⁵⁹ Grade 1---I can remember--- it felt like---it was just like the worst year--- it seemed to me like everybody around me was ten times smarter than me and they would know things and I wouldn't-you know

M.: the teacher used to keep me in the classroom during break - all the naughty kids had to stay in at break.

H.: I didn't really learn that much there... they tried to teach us how to read there – and I didn't really get how to read so that's when they sent me to [remedial school]-I didn't really learn that much that's why nothing really sticks in my mind

The “Otherness” that I refer to, the exclusion in inclusion, is expressed frequently as a feeling of “less than” or inadequacy, and as a sense of isolation. Frank (2002) refers to an “Us and Them” world, highlighting the alienation that is experienced. This is exemplified in the following comment:

⁵⁹ In excerpts from transcripts pauses and hesitations are marked by dashes – multiple dashes suggest a lengthy pause. Where a portion of the original transcript has been deleted, this is marked by dots...

M.: I just find it really frustrating when everybody can do at least one thing really really well and I can't – I sometimes feel like I'm such a moron and I'm so different – its not even like everybody makes fun of me – nobody even knows – its just a feeling – if we're doing an exercise and I won't know what the answer is and everybody else will and I just feel like such an idiot

What is significant in M.'s admission that she feels like an idiot, is that it is her perception alone, no one's behaviour towards her makes her feel this way. In fact she expresses her sense of isolation with "nobody even knows" that she feels this way. This is an interesting contradiction in that she herself experiences an isolation that she admits may not even exist.

The perception was that things were easier for their peers is also common to most of my informants. This too perpetuates the sense of inadequacy and being "Other."

H.: going into a school [where] not everyone did have problems was kind of difficult—no one would understand what I was going through – like if I battled with something then they wouldn't understand why I was battling with this because it was so easy to them

H.: I always feel like it's easier for them than it is for me- I always feel as though I'm battling and they – they fine with it-

H.: I won't understand what the question is – they'll find it a very easy questions and I'll find it a very difficult question -- sometimes I do feel like that

However the sense of exclusion was not always related to classroom performance. H. was unable to go on a school trip due to illness and this

resulted in her being marginalised in discussions when the rest of the group returned:

H.: it was such a big thing that I couldn't go on our one school trip –they went to Zululand and because they were thatched⁶⁰ I couldn't go with so- and then they learnt so much on that trip while they were there and then when they came back they were talking about it – well they had learnt so much and I hadn't learnt it –which was a bit difficult because when they were talking about things I didn't really know what they were talking about –

Most often the exclusion my informants felt was the result of performance that was judged inadequate or of failure. The experience of failure is perhaps the one that is most common to children with LD, and one of their first experiences at school. The literature suggests that this failure occurs both in the classroom, with academic task such as reading and spelling, and outside the classroom with friendships / socialization (Fujiki et al., 2001, Kavale & Forness, 1996, Settle & Milich, 1999). However as can be seen from the stories which precede and the discussion which follows, the informants did not experience the latter. I have chosen to place a detailed discussion of experiences of failure under the heading above (1.1.Mainstream education) as all of my informants only reported failure in the context of mainstream education, and none in the context of remedial education.

1.1.1.Failure

A.: I want to sit down with my paper in front of me and everything and then I'm just blank – I just have like a puff of smoke in my head –I don't know what to say –I don't know what to write

⁶⁰ Thatch is a dry grass used for roofing. H. was allergic dust mites which thrive in the thatch.

Failure is described in the Encarta Dictionary as “lack in success, the fact of being unable to do or become what is wanted, expected or attempted.” The word “disappointment” is offered as a synonym in the Thesaurus, so the experience of failure can be understood as experiencing disappointment (Levine, 2002, Riddick, 1996). Many children with LD are in a system that perpetuates this disappointment and sense of failure, a system that does not encourage them “to see themselves as victors, [to] capitalize on strengths” (Sternberg & Grigorenko, 2000:6). For A. this experience of failure was what may be considered the ultimate school failure – he had to repeat a grade, the only informant who did. Although failure is for most of my informants a daily experience, it is not one they dwell on in the interviews. All but one informant mention experiencing failure in some way, or feeling “stupid,” which I have chosen to analyze as an experience of failure.

In some instances the perception and experience of failure is only that in relation to the performance of others, for example either high expectations or high achieving friends.

M.: I got my mark and I was really disappointed because -I thought it was a really easy test and I thought I would get at least an A [meaning 80% or above] but I got 75 and even if its not a fail its like a fail because of standards and everything – anything below 70 for me is like a fail – its just like everybody else is getting these really good marks an you’re just like wow 76 or whatever – it’s so disappointing

In any other another context 75 is certainly far from failure! From an objective point of view a mark of 75% is not seen as failure, which in fact in the classroom would be below 40%. It is therefore the context and who and what one is comparing performance to that dictates what failure is. The yardstick therefore changes depending on the context: in a context of high achieving friends, the sense of failure comes at a very different point to in a context where one is comparing oneself to others whose performance is the same as or worse than one’s own.

Fear of failure was another common experience. Both M. and H. show this quite clearly in the collages submitted as part of the data. S. and A. both expressed this in their audio journals, particularly a fear of failing me as the researcher. This is evident in such frequent comments as *I hope you like this*. B.'s reticence to open up in the interviews, mentioned above, is perhaps also an indication of his fear of failing me as the researcher, a fear that he may not give a "right" answer. This despite the assurance that this was to be his story and therefore all he had to tell was his experiences. I have dealt elsewhere with my concern about the data that I received from B., and what I suggest here is that this reticence was in itself useful data. B. did not admit to experiencing failure. However he does acknowledge the move to remedial school was *because I had real difficulties*. The nature of his responses (discussed in the previous chapter) also suggests that he not only had experienced failure but that he found this too difficult to talk about.

S. describes "problems" rather than failure. She does not describe the experience of failure but rather justifies or rationalizes decisions that by another might be explained as failure:

S.: I stopped doing Zulu – cos we had to do Zulu – but I stopped doing it cos I just found that was too much of a workload on me – and also with remedial I had also a lot of work –cos in std 4 [grade 6] I started with Mrs. P and I went to remedial with her and it just became too much for me and my mom said – OK stop Zulu - that's one of your baddest subjects – so I stopped

It is significant to note at this point that although the initial experience of failure was on entering school, or in the junior primary grades, for the four informants who left mainstream education for a period to attend remedial facilities these experiences diminished, but did not disappear on their return to mainstream. They carried back with them the sense of inadequacy and difference:

H.: it was kind of difficult—no one would understand what I was going through— like if I battled with something then they wouldn't understand why I was battling with this because it was so easy to them...and they all seem to understand questions fine- but then I won't understand what the question is – they'll find it a very easy questions and I'll find it a very difficult question

M. describes how her reaction to a poor mark on a maths test colours everything that follows. She had received very positive feedback for a classroom presentation and a history test. However there was no sense of achievement or joy at the good marks because this was overshadowed by her disappointment over a maths test mark Note how she measures her success by comparing her performance to her peers:

M. : I felt so worthless and then I got my history back and I was quite happy until everybody got their tests back and everybody in the class got good marks as well because we had this history thing and I got 100% and I was feeling good about that for about 5 seconds and then everybody else got theirs back and they got the same mark as me and I felt like—it wasn't an exceptional project because you know some people didn't actually work at all---and I couldn't be happy about the good conference which was much more important than one little maths test – it was a stupid thing- its just – my marks have been like- they've dropped so much and I ask myself why and I can't say oh well its because there's something going on at home or I haven't been taking my R or anything – I can't think of any excuse – it ---just makes me feel pretty worthless- there's no reason why I shouldn't be getting good marks like everybody else- I'll get a mark and I'll be like Ok with it – it'll be disappointing but I'll be like OK fine and then everybody else gets much much higher marks – its just so depressing-

M. : it was almost like I felt out of place if I did badly –I just thought why can't I be like everybody else – why can't I just listen to instructions and follow them properly

She refers to an attempt to put a door-stop in place that failed when she put it in the wrong way around:

I just felt like everybody would have known how to put the door stop in

Her sense of isolation and feeling out of place is clear; she expresses her desire to be “like everyone else.”

In addition to experiencing failure, all informants reported experiences of the consequences of failure, sequelae such as humiliation, teasing, and low self esteem (Levine, 2002, Riddick, 1996). M. describes one occasion when she experienced failure and the humiliation that accompanied it. It was during an athletics race and she miscounted the laps she had run and stopped before completing the requisite number of laps:

M.: I enjoy [running] and I overtook the second person so I was coming second and I stopped running- I felt so stupid (voice starts quavering) and –I dunno I had to run again and I was so incredibly tired (°°)⁶¹ – and I just felt like such an idiot – and I spoilt the whole race for myself (crying) cos I wasted all my energy – and if I just thought about it – I might have actually stood a chance – it was just so annoying

The experience of failure is frequently linked to the experience of humiliation as the latter is often a consequence of the former. However in the following section I provides examples of humiliating incidents that

⁶¹ (°°) symbol used in transcription to denote tears

reveal the resultant “scars” (Edwards, 1994) in the emotion that accompanied the telling of these stories.

1.1.2.Humiliation

The experience of humiliation is one that each informant was able to recount in detail, despite sometimes choosing to tell of an experience that they had had 8-10 years previously. It is the humiliation narratives that form the core of M.’s story particularly. An example of this is in M.’s recounting of one of her earliest school memories, something from the first grade:

M.: I can remember one thing in particular we had to do-it was a test thing and we weren’t allowed to rub out what we had written-and we were supposed to write son...not the sun that shines in the sky and everybody knew that it was S-O-N and I didn’t – I wrote S-U-N—and like- they just (°°) I felt so stupid

Such detailed recall and the accompanying emotion, reveals the depth and power of the experience. H. describes an incident where her word finding difficulty resulted in embarrassment and humiliation:

H.: I really battle with ...remembering words-I could’ve used a word in the sentence before and the next sentence I’ve forgotten it – I can’t remember what it is and then I’ll stand there going-hm-um-um- and I can’t remember it and it really really bugs people and it bugs me—I’ll never forget the day that I went to a wedding and I was talking about something to a whole lot of people and I had just used a word and then a couple of sentences later I couldn’t remember the words – the word was aneashtetist – and when I explained to them what the aneashtetist does and –to try get the word cos I couldn’t remember it- they said “oh well you’ve just used the word – you should know what it is”-I don’t think they

understood how they made me feel-I felt really conscious of the fact that they were kind of making a joke out of it but it wasn't a joke to me at all—because I am very conscious of the fact that words don't come to me like they come to other people

Frank (2002) describes how frustrating it is to have difficulty with word recall or word finding. What is illustrated so clearly in the above quote from H. is how painful and humiliating it can be too when conversational partners do not understand.

Then there was the humiliation of being caught cheating in a test:

M.: I can remember there was a geography test and...I had the notes in my desk and I put my rubber in my desk so I could open it⁶² to look at my notes----and then ---she⁶² called me up in front of the class and she asked me why I hadn't learnt--- and said she'd leave the mark on my report and I'd know ----I'd know that it wasn't my mark (sobbing⁶³)

She also describes incidents which result in “feeling so stupid” and “feeling dumb” are reported by M.:

[I felt] 'like I'd done something really huge—even though it was stupid and tiny – it's little things like that that get to me and just make me feel dumb—little things like that happen like all the time and I laugh about it and I joke about it but inside it still feels really really horrible

⁶² Again the teacher is only referred to in the third person pronoun, and in a sense is depersonalised, even de-humanised. M. does not mention the name of the teacher or even refer to ‘the teacher’

⁶³ At this point the interview was abandoned as M. was too distraught to continue. This was retelling of an incident that had occurred 6 years before, yet was still so upsetting., an indication of the level of humiliation and embarrassment suffered at the time.

1.1.3. Teasing

Literature links teasing and bullying (Humphrey, 2002). Although none of the informants reported experiencing physical violence all reported experiencing teasing, a form of verbal bullying. Children tease those who are perceived as “different.” The literature stresses the impact of teasing on children – particularly those who are teased because of poor scholastic performance. All of the participants experienced teasing, although one, B., did not initially acknowledge this.

A.: you have your enemies that are gonna want to tease you and stuff ...the way you do something –.....–they go on about the most stupid little thing—just try and find something to tease you about – like you did something wrong and you asked a stupid question –they start teasing you-

B., who initially said he’d never been teased, implied otherwise when he said: *I’m not that kind of boy who likes people teasing him and all that.* He has also chosen not to disclose to any of his friends that he is taking psycho-stimulant medication for fear that he may be teased, as he acknowledges he has been teased about this before. All of those who were at some stage medicated with psycho-stimulant medication experienced teasing about this where they had shared this information. This is discussed further in section 2 below.

Only one informant did not link the teasing directly to his or her learning difference or scholastic failure. ST was teased but does not link this to her learning difference at all, but says it was about other issues. She describes how the teasing “got to her” and eventually affected her work as well.

All of the participants who experienced teasing had developed a philosophical attitude towards it, commenting that as there are always likely to be those who will tease anyone who is different, the best way to deal with it is to ignore it. These words possibly reflect parent and teacher’s

advice to them, but nevertheless all said that they were no longer experiencing teasing at the time of the interviews. All seemed to have built a small but strong circle of friends where a trust bond served as a form of protection against teasing.

Despite the experience of failure, and the resultant teasing and humiliation being common to all my informants, in their narratives they do not dwell on this. Proportionately the data includes far more information on friends and friendships and teachers and teaching than about failure. What this suggests, I believe, is that failing to cope, which to educators is the big issue, the one we jump in and try to fix, is not as big an issue to the children as friends, friendships, pleasant teachers and innovative learning experiences. I return to this point in the following chapter when I suggest a reframing of intervention goals to take this into account.

1.2. Specialized education: Experiencing inclusion in exclusion from mainstream:

The most interesting and, I believe in view of the inclusive education focus in South Africa at present, most relevant finding was that of extremely positive experiences of those children who spent time in remedial facilities. By all accounts they were “excluded” from the mainstream for failing to “measure up” and cope in a system that is not geared to their different learning style. For each informant there was a period of assessment and a formal “diagnosis” of LD as a result.

All 4 of my informants who were in remedial school or units were placed there prior to 2000, and only 1 (B.) was still in a remedial school at the time of the first interview (2003). The *Education White Paper 6* that outlines the way forward to inclusive education was published in 2001 (DOE 2001), so inclusive education was not policy or practice at the time my informants were referred to remedial schools or units. The two girls spent two years in the junior primary phase in remedial school and the two boys had both been

placed during the senior primary phase. All however returned to mainstream within 3 years of their placement.

Dane (1990:54) mentions that:

Assessment may mark a turning point in a child's life by leading to positive intervention and increased access to services and opportunities, or it may provide a stigmatizing label that leads to a downward spiral of limited options.

Archer and Green (1996:127) suggest the process of assessment and consequent labeling is important:

The relief of having discovered or been assigned an identification, which implies belonging somewhere, may free those concerned to make a more realistic evaluation of the situation and to take action. This may at least partly explain public enthusiasm for the term 'dyslexia,' which gives the security of a category , while remaining mysterious enough to avoid stigma

It is this sense of belonging that I believe the experience in remedial school provides. Without exception each informant said that the move to remedial school / unit was their first experience of not being the “Other,” their first experience of “sameness.” It was in fact the positive turning point referred to by Dane.

H.: I found it easier to go into RR because everyone was like me – they all had problems

M.: I was much happier there-- I don't actually know why –I didn't really know then—it was just having friends – and it wouldn't matter if I didn't know and just said putt instead of put

In other words for her the “norm” had shifted – what was considered failure in a different context or environment was now viewed differently; in fact it did not seem to matter.

The informants' understanding of the move did, however, perpetuate the "deficit focus" The understanding of the reason for the move from mainstream was shaped by what their parents told them. A common experience was that they felt excluded from the decision –making and that they had no control over it:

M.: At the very end –I just remember you telling me that you wanted to send me to RR because you didn't want to regret it in the future – you didn't want to think "Ah, I wish we'd done that"

B. too does not acknowledge that the move was for his benefit initially; he felt it was better for his parents for him to go to remedial school. The reasoning was that there he would be "made" to work and get good marks.

B.: I dunno – making me learn – making me get work better – get good marks and all that

This suggests that he felt external forces were responsible for his succeeding and, by implication failing. I return to a detailed discussion of this later in the chapter.

Despite this all reported settling and feeling happy there.

B.: I think it was better for me to go there – because I had real difficulties – now I'm in [mainstream high school] and RR's actually helped me quite a lot

H.: I can't actually remember---I think I knew it was because I couldn't cope---that's how I understood it---But later on I realized why--- it was because I couldn't cope – ja- RR was just a much better environment for me for that time

B. expresses an interesting contradiction:

B.: RR is much easier—there's more subjects—that's all I can say.

It seems a contradiction to say it's easier, as there are more subjects and thus by implication more work.

Friends and friendship, or social success, remained important for each informant:

M.: I can remember I felt like-really comfortable there at RR--- in the beginning of grade 2 I was really insecure –I didn't know where I was- –in grade 3 I was much more comfortable—I made more friends-

Strong friendships were formed in the remedial school or unit, friendships that have lasted in at least 2 cases into young adulthood. Even on return to mainstream, they tended to socialize with other learners from the remedial school:

B.: it was fine – making some friends and all that – I stuck together with - the RR pupils only – and then they started to get some friends and I started to get some friends – and then all their friends and my friends are together and we stick with them

Note how initially friends were also learners with LD, but then the circle expanded and in the wider circle new friendships formed.

Bear et al. (1998) suggest that in fact the academic domain or school experience has an important impact on the development of a global self worth. For each one the move to remedial school was the beginning of self-acceptance, a realization that they were not “less than,” inadequate or incapable but that they were just different; that there were other learners who were different like them and therefore in that environment all were the same. It gave them a sense of belonging to a group, rather than of marginalization. Every one rated their experiences there as extremely

positive and gave their years in the remedial environment a higher rating than in mainstream, regardless of subsequent success in mainstream.

Schöpflin (2001) suggests collective and individual identities influence each other. The self is constructed partly through collective activity:

The best that collective identities can do is to offer discourses that explain the incompleteness that partial agency produces, to provide narratives that make sense of success and failure....

This lends support to my contention that for these informants their sense of self shifted from “Other” to “OK” after being in an environment where the collective all had similar learning experiences.

I am not advocating a total re-think of inclusive education as a policy. However I am concerned that decisions are being made without taking into account the learners’ views. I am concerned that in our zeal to embrace a democratic, rights-based and therefore inclusive education system we may be throwing the baby out with the bath water. There are indications that excluding learners, putting them in an environment where there are other learners who share their learning styles/ differences/ disabilities, may, in fact, be a good thing. Therefore perhaps the greatest disservice currently is the push to include learners with mild to moderate barriers to learning in the mainstream. In *Education White Paper 6* (DOE, 2001) reference is made to the need to move away from segregation on the basis of disability, yet it was only in being with other learners with LD that my informants felt a sense of ‘normal-ness’ in their ‘sameness.’ It is quite evident from all four informants who experienced ‘exclusion’ in the sense of being removed from a mainstream school and placed either in a remedial school or a remedial unit in a mainstream school that this was the most positive experience for them. By keeping these children in mainstream they are likely to continue to feel marginalised and different; to feel less than or inadequate. By having to complete tasks during hours that are set aside for recreation such as school breaks or after school deprives them of

opportunities to socialize with other children. Research abounds with reference to the poor socialisation skills of children with LD (Fujiki et al., 2001, Kavale & Forness, 1996, Settle & Milich, 1999). Yet when the work load and homework load was as heavy as it was at remedial school, none of the informants saw this as punitive – “we were all doing all this work together” so there was not that sense of deprivation that came in the mainstream.

Gerber and Reiff (1991) stress that experiencing success at school is important for later adjustment and success. I argue that special school placement allows for the experience of success. Inclusion has the child placed in a group where he is compared (unfavourably) to others, by both peers and the teacher. This results in him being treated as “less than” or “Other”, especially in classrooms where teachers are not well equipped or adequately trained to deal with children who are different (Sternberg & Grigorenko, 2000:24). For my informants this was the beginning of a realisation that in that environment they were no longer “Other” but the same as others, it was the beginning of acceptance and building of self-esteem. Without exception they all reported those were the best years, the best teachers, the most positive experiences of their schooling. Those were the only teachers they reported remembering or referred to by name, and those were the years most highly rated on a scale of 1-10 as they reflected back: for 2 of the participants this reflection happened in their final year of school, some 8-10 years after the remedial school experience, yet they still recalled this most favourably, and their favourite teachers still came from this time.

1.3. Experiencing support :

1.3.1. Teachers and teaching

The role of teachers and teaching is paramount in both the experiences of exclusion and inclusion, regardless of school context (again I use these terms not to refer to educational practice or policy but to refer to the way

the informants felt – either excluded or included; either Other or Alike). In the discussion which follows I highlight the informants’ experiences with teachers – the good, the bad and the ugly. I also discuss “teaching” both as it refers to what happens in the classroom, as done by a teacher, and as it refers to the extra-curricular support that each informant found so necessary. It is the latter form of teaching that raises interesting questions about how well children with LD are actually served in the current education system.

Only one of the participants did not spend a period of time in a remedial unit or remedial school. However she received remedial support on an on-going basis for three years. Three informants attended a remedial school for two to three years, two in the junior primary phase and one in the senior primary phase. The other informant spent three years in a remedial unit in a mainstream school, where he repeated a grade. All returned to mainstream schools, three to private school and one to a state (government) school. Bear et al (1998) found that children judge their academic performance on teacher feedback. All informants had both positive and negative experiences with teachers. Initial experiences were of punitive teachers who did not understand their difficulties or who lacked the patience to provide support. Recall M.’s experience of being “punished” for her slow work rate by having to stay in class at break, something that was associated only with “the naughty children.” She too in her recounting of her early experiences never names the teacher, but only refers to her by using the feminine pronouns “her” and “she.” This was also noted in both A. and H.’s reports. This is not merely a matter of forgetting a name over time as both H. and M. remembered names of other teachers from the same period, but teachers who were in the remedial school and therefore not associated with the emotional trauma of their early school failure. B.’s experience of *strict teachers* in mainstream suggests a perception of teachers who were inflexible, rule-bound and not understanding. In every reference to mainstream teachers, whether before his remedial placement or after his return to mainstream, his experience is of stricter teachers.

Sternberg and Grigorenko (2000) suggest teachers in mainstream are ill-equipped to deal with learners with LD. All informants link their early difficulties to a teacher's inability to teach them:

H. *They didn't teach me anything there*

A. *I never really got how to read*

Every one of the informants sought support from both peers and parents, and in each case preferred this to seeking support from teachers (see section 1.3.2. Peers and parents below). This reluctance to seek help from the teacher is unexpected, particularly from S., as she reported experiencing positive support from teachers through the primary school. Recall S. was the only informant who stayed in a mainstream school and received remedial support after school hours, rather than spending time in a remedial unit or school. She accredits the additional support received then to better teacher involvement in the learners' lives: *they knew who was in remedial* whereas in high school: *they don't actually notice*. She also suggests workload of teachers is a factor which allows teachers in the primary school to spend more time with individual learners:

S.: *Well in primary school most of the teachers knew who was in remedial and who had a problem and they would help you along – in high school they don't really help you along – they don't actually notice and stuff – if you don't understand you must just ask – youcan't really go and just ask ... you don't really do as much work in primary school so they could see if you understood it and they would help you...*

It is also an indictment on A.'s teachers that he prefers working at home, even if it means excessive amounts of homework, because he feels this is where his best support lies:

A.:I like doing most of my work and homework at home – not only because I’m at home and by myself and can concentrate – I can close my door and lock myself in my room and then just concentrate and then be able to just work nonstop because then if I do get stuck and do have a problem then I can ask one of my family – and they know how to help me in the way that I need to be helped – so they can show me the problem and I can carry on and go on with my homework – not like at school when the teacher sometimes can’t help me the way I need to be helped – so that’s why I prefer to have lots of homework ... I d rather have the work and then get it explained to me properly if I get stuck but I do like to play and like go to do sports and stuff in the afternoon –I stay up quite late in the night doing a lot of homework

However he acknowledges that he sometimes gives the teacher an indication that he does in fact understand when he does not:

A.: then I don’t enjoy doing that work cos then I can’t really understand and even when I ask – the teacher –I don’t really understand what to do and then they explain it another way to me sometimes I still don’t understand then I say OK- that’s fine and then again I do the work and I don’t fully understand that and then I don’t get all of the marks

Despite the fact that teachers were usually seen as a “last resort” to seek help from, all informants did describe favourite teachers and their qualities. Without exception all four of the informants who attended remedial schools described one or more of the teachers there as their favourites even though two had been out of that environment for more than 6 years and therefore had had many other teachers since then, particularly in high school where they had been exposed to as many as eight different teachers each year due to subject teaching. The only informant who had a favourite teacher in a

mainstream school was S., who did not attend remedial school but stayed in mainstream.

The following qualities were used to describe favourite teachers: they were supportive, understanding, had a sense of humour, and good classroom control. In each case the informant is spontaneously describing a teacher from the remedial school or unit s/he attended:

B.: They don't shout a lot at you – they give you more time to do things –if you're not there to do a test they cancel the test till that person comes back

They understood if you had to leave the class for occupational or speech therapy and *if you were not there to do a test they'd wait until you were back* because they knew you were there in that school to get all the support they could provide.

A.: ... in PP I got – whenever you ask for help- or you knew all the teachers would just give you the help so with every class – every teacher the help was there for me and ---can't remember anything particularly –ja

M.: maths and english were the best ----I remember story writing I used to love story writing ---especially in grade 2 –she'd give us pictures and we'd have to write a story... I didn't actually have a problem spelling---we could go to the teacher and ask her to spell any word—I knew I could ask her any word so I could use any word I wanted to –not just words I knew

What is interesting here is that written language is one of the areas that a child with LD finds most difficult (Poikkeus et al., 1999). Yet the development of this skill is encouraged in such a positive way that what one would expect to have been a negative experience is in fact a positive one. For this particular informant this was the beginning of a real passion for

language and writing. Despite the fact that the teacher gave support by providing words and spellings, this did not result in her not learning to spell.

Other qualities of favourite teachers include patience, understanding, having a sense of humour, having fun but still maintaining control of the class. I return to a discussion on teacher control in the following chapter because the lack of control is one of the characteristics that my informants blamed for their learning difficulties.

M.: [My history teacher] is a good teacher- she's very accommodating to those who don't work fast –she doesn't really push them – and history is like writing three page essays in 50 minutes – she should – she's quite a good teacher ...the accounting teacher's very good –she's very patient –she's not always serious the whole time – she will laugh with us - but the maths teacher sometimes gets a bit out of hand with his chirps which can be very insulting but he doesn't realize it – I don't think he means it but he likes to be funny and impress the funny clowns –so he gets a little bit insulting with his chirps – but otherwise he is quite a good teacher

S.: Good teacher must be spontaneous- make lessons fun and care

1.3.2. Peers and parents

Perhaps one of the most startling findings for me, as an educator involved in providing support for learners with learning disabilities, was that for each participant, the teacher was the last place they went to for support. In all cases, they sought help with tasks from parents first, then peers and only if all that failed, went to teachers. This is concerning in what it says about the role of educators in the management of learners needs.

H., when she needed specific support around the learning of new concepts, went to her parents for that help first:

H.:I can remember one time when I was doing division and our teacher couldn't explain it to us – wasn't explaining it to us properly and then I came home and my dad taught me long division –sometimes I take a long time to grasp a certain concept – once I've grasped it then it's fine – the long division was just so much easier for me – and that made quite a big difference—I still do long division that way -I just find it easier –she did eventually land up teaching me but I would never have understood it the way she had taught us

Recall how S. mentions that she requires the teachers to *explain it in a way that I will understand it*, yet she still only uses the teacher as a last resort. She goes to her parents first, then to her peers:

S.:If I can't do it then I'll go to my dad or to my mom sometimes- – if I sort of understand then I'll ask my mom- or my sister - I'll go to someone in my family- or if none of them understand I'll go to the teacher and ask—and if they don't explain it to me and I don't understand – I'll go please explain it to me again – she'll have to explain it to me until I understand it

S.:Maybe I'll ask one of my friends if they understand it – if not then I'll go ask the teacher – please explain that again to me- I didn't understand it

A. seeks support from both his parents and his peers:

A.:I will come home and ask my mother –cos she knows me –she will help me getting through that work in a way that I will understand

He identifies his mother as the person who knows him best, and therefore the person in the best position to provide exactly the type of support he

needs, in a way that he can understand. A. acknowledges that peer support is sometimes given grudgingly:

I have a short term memory [problem] and its quite irritating with my short term memory cos when I get taught one thing in class... or I get told something or get explained something to me and then ... a day or two late or maybe an hour – it depends how well I was listening at the time I would have forgotten most of that – but not all of it but most of it – so I'd have to [say] to my friends – hey what did that teacher say again –or what did that friend say again and ...sometimes I ask my friends and my friends start to get quite irritated with me at times

M. however experienced the most significant support from her peers:

they would be like learning and help me through and help me with things I didn't understand

She also credits her peers with her academic success, suggesting it was the high standards they achieved which lead to her working harder to keep up.

Norwich and Kelly (2004) found that 15% of their sample sought help from friends in the classroom. However their sample included learners who had mild to moderate cognitive impairment. Another significant difference was that the learners in the Norwich and Kelly (2004) study had access to teacher aides in the classroom as well.

Therefore it is apparent that what educators provide in terms of support is not highly regarded or valued by my informants, whose 'diagnostic labels' would suggest are the learners who most need it. They choose to seek that additional support from peers and family members, which begs the question: Why? A. expresses this clearly: his teachers do not know him as well as his family and therefore are unable to explain things in a way he can relate to or understand. The same sentiment is expressed by both H. and S.,

who suggest only parents explain “in a way I’ll understand.” M. was the only informant who did not report experiencing **better** support from peers and parents, although she used peers for support.

I believe this underscores the importance of a good social network, as friends provided important academic support for each of my informants. There is much reference in the literature to poor social skills in learners with LD, particularly those with concomitant ADHD. Tur-Kaspa (2005:319) maintains:

In sum, children with ADHD have difficulty establishing, and maintaining satisfying interpersonal relationships with peers. They tend to be bossy disruptive, easily frustrated, ...it is not surprising therefore that they have few, if any, friends.

However for each of my informants I found the converse to be true: each described deep and long-term friendships and each benefited from these; they credited friends with helping them in their academic endeavours. M. goes as far as giving her friends the credit for her own academic success.

1.3.3. Other forms of support

There were other forms of support my informants accessed, such as exemption from the third language requirement. This was part of the school curriculum for all informants, being policy at the time. For all my informants the first language was English, Afrikaans was offered as a second language at primary school level and by senior primary (grade 4) a third language was introduced: in KwaZulu-Natal this language was isiZulu. Both H. and S. received a formal exemption from isiZulu and therefore used the extra time on the timetable to catch up with other work. H. later applied for a time concession for exams and continued to use the time concession as a support through her final school- leaving exams and tertiary education.

2.Secrets and lies: Experiencing judgment:

All of my participants have been diagnosed with LD and ADD or ADHD and are currently or have been on psycho-stimulant medication for the ADHD component. A common theme that was noted in my data was the issue of medication and the experiences of my informants relating not only to the efficacy or otherwise of the medication but also their experiences of stigmatization. What emerges quite clearly in their narratives is a story we perhaps do not take seriously enough when we engage in academic debate: a story of shared secrets, fear, and judgment.

I believe much of the data is powerful enough to stand alone. The excerpt below, which is taken from the diary of one of my informants, highlights a number of **recurring themes**:

today in RE we were doing drugs and stuff –drugs of abuse- and we would have a whole lot of types – the teacher would be like “ the easiest example of these is like diet pills” and then somebody would be like “Oh Ritalin is also like that – it also makes you not want to eat’ and you just feel like hitting them - like really really hard – because they’ve watched one little thing on Carte Blanch⁶⁴ and they think its like the worst thing since Robert Mugabe⁶⁵ – its so pathetic – they’re just so ignorant and then – we’d do something else and somebody would bring it up again and it’d be like “ oh ja it makes you really high but it only lasts for a few minutes” and: “Ja, Ritalin’s addictive:” and “Ritalin makes you high if you snort it” and- it’s just so annoying because they don’t know anything –and they don’t think – and because its like the top set I don’t think any of them are on it- I think I’m like the only one – they’re all naturally clever – and then you’re feeling down in the dumps because you’ve

⁶⁴ Carte Blanche is a magazine programme presented on a pay channel in South Africa. It deals with contentious issues across a number of fields.

⁶⁵ Robert Mugabe was president of Zimbabwe at the time. Many of his policies were extremely unpopular and discussed extensively in the South African media. Reference here reflects the growing political awareness of an adolescent.

got really bad marks and then they go and mess it up and they go and say something that's so annoying its like –shut up if you don't know what you're talking about –like – and I've noticed that – its amazing how ignorant people are – they read one article and then they think they know everything – you can't do that – you have to research it properly before you can open your mouth- especially on such a sensitive topic like that – ja – the ignorance – it just amazes me-

The following feelings are reflected in the above comments: *frustration* at the negative attitudes of others; *sense of injustice* at the association with drug abuse; *ignorance* of others, particularly with regard to how the medication works; *anger* at lack of insight perpetuated by media; *sensitivity* at the insensitivity of others; *hurt* and *inadequacy*. Each of these feelings has been discussed further and corroborated with additional comments from research participants that support the point in another paper.⁶⁶ In what follows I provide support from the data for these sub-themes.

The first theme is the **perceived (negative) attitudes of others**. The informant's **annoyance** is highlighted in the main excerpt ("you just feel like hitting them - like really really hard). This annoyance is clear in the comments made by another participant; note particularly how both stress the adjective "really":

H.: and another thing that really really bugs me is people that think people that take Ritalin are all hyper and they'll – if someone's all enthusiastic and they have a lot of energy they say "I really think you should take Ritalin" or something but they don't actually know

⁶⁶ Flack,P (2004) Is anybody out there listening? Paper presented at the National Learner Support and Development Conference, Bloemfontein, September 2004

how Ritalin – what Ritalin does and they don't actually use it in the right sense but it really bugs me-

Note the reference to “normal” behaviour such as enthusiasm and being energetic! She also expresses her irritation at people who are ill-informed. However despite the irritation, she does not disclose that she is taking the medication (this is discussed below) and therefore makes no attempt to change the perceptions of the “ill-informed.” The desire to keep the secret outweighs the desire to provide information with a view to changing attitudes.

Another predominant theme related to the negative attitudes of others was the **association with drug abuse**: The judgments made about those who take Ritalin and association with drug abuse and illegal drug use is another theme noted in the data. In the excerpt above the child quotes comments made by peers that reflect this. I repeat these here:

*M.: it makes you really high but it only lasts for a few minutes ...
Ja- R's addictive...R makes you high if you snort it*

Amen (2001) and Fonagy et al. (2002) suggest that children with ADHD who have a history of medication are in fact less at risk for substance abuse. The public perception therefore reflected their **lack of knowledge**. All participants who were either currently on Ritalin or who had taken it in the past expressed their frustration and indignation at comments made by the “ill-informed.”

M.: they're just so ignorantshut up if you don't know what you're talking about and I've noticed that – its amazing how ignorant people are.....the ignorance – it just amazes me-

H.: but they don't actually know what Ritalin does

The excerpt below is taken from a journal entry of one of the participants, and not a transcription of an interview. It is for this reason that the punctuation and capitalization appear as she wrote them. Both of these features speak volumes about her feelings at the time:

I am very frustrated. I have learned that people who are not prepared to learn about a subject, people that couldn't be bothered, are the people who walk around saying things that don't make sense, that they have concocted in their brains but have absolutely no idea whether it is true or not, they just make it up and assume it's right because they think they know everything when they don't. Phew, stop for breath. In most cases this wouldn't offend anyone, but in this case it does, it offends many people that I know including myself.

*So, to get to the point of this entry, today, my friends were talking about a guythey were saying how weird he was, how high pitched his voice was, and picking out the bad things about him instead of the good ones....., while they were talking about how weird he was, one of them mentioned somethingwhich made me furiosus: "Oh , he's on that stuff, you know, for over active people, what's it called again?" For starters she doesn't even know what the stuff's **CALLED** never mind anything about it!!!!!!!!!!!! I get really annoyed when people do that because they don't **KNOW** so how can they say things like that. What really annoys me is that you tell them that its not for hyper active people etc. and they **STILL** assume!! growwlll!!*

What is so clear in the entry is the informant's tremendous sense of indignation as well as the injustice of judgment being passed by people who are ill-informed and thus unqualified to do so. She mentions her frustration, her anger, demonstrates her contempt for people who "concoct" and "make up." By referring to the many people who are offended she declares an "in-

group membership” or shared identity: she feels she can speak for the many who are offended, not just for herself. This serves to reinforce the argument raised above about the importance of the shared experiences in a remedial environment. This extract also clearly illustrates the “Other” concept described previously where I refer to exclusion in inclusion: the marginalization and setting apart of the child who is different.

The power of the media is well documented. It is perhaps the media that shapes public opinion more than anything else. The informants allude to the information available in the popular press particularly, and in both the excerpts below imply that this information perpetuates the misperception and lack of knowledge rather than adding insight and knowledge.

M.: because they've watched one little thing on Carte Blanche ...they read one article and then they think they know everything – you can't do that – you have to research it properly

Comments made by peers and teachers about psycho-stimulant medication are described as hurtful and insensitive:

H.: and they don't think

M.: especially on such a sensitive topic like that

2.1.On disclosure

Another significant issue that warrants further discussion is the issue of disclosure. Many children who are medicated choose not to reveal this to teachers or peers. The drug is taken at home before the school day starts, especially children who are in a mainstream environment. Reasons for this include the perceived lack of understanding discussed above.

H.: that's probably why I haven't told anyone that I take Ritalin – only M. knows and that's all the people that I actually want to

know about it – because they actually don't need to know that I take Ritalin and they'll just tease me and just makes a big thing to talk about and joke about and I don't need someone to joke about that because I think it's a very serious thing for me –

Note that the “M” referred to is a friend who is also taking the same medication for ADD. She too has not disclosed that she takes psycho-stimulant medication. That this is such a tightly guarded secret is illustrated by the following vignette:

M. was required to present an oral in class on any contentious topic. She chose to discuss the issue of medical management of ADHD, something that she felt very passionate about. She decided to tell her own story, but presented the story in the third person (Let me tell you about my friend Jane: she has ADD...). When the oral was over one of her classmates shouted “I know who Jane is – it's H, isn't it?” The “H” she referred to was indeed someone who used psycho-stimulant medication to manage her ADHD, but no one in the class even hinted at the possibility that M. was in fact telling her own story. Her closest friend, who knew, remained silent. M. denied that the story was about “H” but did not at that point say it was in fact her own story. The eagerness of some of the classmates to identify who she was talking about reinforced for her the need to continue keeping the secret. In addition to this, M was aware of two other people in the class who had disclosed to her that they either were using or had used psycho-stimulant medication in the past, and neither of them admitted this in the ensuing class discussion, but also chose to “keep the secret.”

Another participant reported that disclosure was not an issue in an environment where he did not feel different or “Other” as this was a shared practice:

A.: Um- well back in PP or wherever there were a whole group of people who took it and they had like a separate place where you had

to take the Ritalin and stuff - so it wasn't really a big deal back then but I've never really had anyone say anything because I usually just take it- for a long time I was taking like two in the morning at home - before I went to school and then I don't talk about it or anything and no one knows and so its fine – so I've not really experienced being teased about it or anything

What is quite apparent here is the “Ritalin culture” of a school environment where medication is the norm rather than the exception. There are “Ritalin rituals” such as a special place to take the tablets, an in-group with whom to share this. Outside of this environment he too has chosen not to disclose that he takes Ritalin

The reluctance to disclose is noted in the comments of other participants. The reasons given are the same: **the insensitivity of others, the teasing, the perception or misperception of mental illness/ being “crazy” or deficit in some way, as well as the insinuation of addiction.**

2.2.Efficacy:

The participants all made a comment about the efficacy, or at least their subjective opinion of the efficacy:

*H.: I think it helps a lot and I know the difference when I haven't taken it and I seem to not concentrate in class – just helps so much for me and it's made such a difference in my life – at school and even sometimes when I've had to do drama or –you know learn words for a play or anything like that- it just helps me –I don't know learn the words more easily – I don't know what I it is but it really **really** seems to help*

M.: its just –my marks have been like- they've dropped so much and I ask myself why and I can't say oh well its because there's

something going on at home or I haven't been taking my R or anything – I can't think of any excuse

The implication here is that the high marks are due to taking Ritalin and if she stopped she would expect marks to drop – that would be a suitable explanation for the drop in the marks.

A.: At school today I was very tired so I can't – I could concentrate properly but I was - I had a late night last night and was pretty tired- even though I took my Ritalin and everything but – I could sort of concentrate but I was tired – I battled – but not really battled a lot – but like –I sort of battled to concentrate and also – I don't know what it is but I never felt that much like working because – I was so excited because – er—I just moved –

Here too there is an implication that because he took his Ritalin he should have been able to concentrate – and even reasons that *I could sort of concentrate*. He eventually reasons his way around to why he couldn't concentrate – he had just moved rooms and was excited. What is relevant here is how he brought up the issue of Ritalin and by implying that he couldn't concentrate even though he had taken it, he was left looking for another reason for his poor concentration.

3. The blame game: externalizing the problem:

The theme that I call “blaming” or “externalising the problem” was only revealed in the informants' narratives after returning to mainstream and was not apparent during the first phase of scholastic difficulty and failure. At this initial point they describe the problem as intrinsic, as a result of some inherent weakness in them. On return to mainstream after a period of remedial intervention, there is a subtle shift from *I couldn't learn how to read* to *the teacher couldn't teach me*. It seems therefore that after being in an environment where all learners shared similar histories and

difficulties, where each one was no longer the “sore thumb” in the classroom, they began to play “the blame game.”

Despite apparent recognition of specific strengths and weaknesses in relation to peers at school, these children frequently refer to their “failure” or difficulties as being the result of poor teaching, either an inability of the teacher to explain things properly *in a way that I could understand* or some technique of teaching such as soft voice or inability to control a class:

A.: I can remember the teacher had a very soft voice so you couldn't always hear her – and she didn't really have a good way of explaining things so I never got to grasp it – I didn't understand it

S.: I don't grasp it easily and then he wasn't very good at explaining things

H.: Just the history teacher who goes off the topic all the time --um – and sometimes with the mixed abilities class again some of the people mess around quite a bit –

This view of the teacher being responsible for their difficulty or failure to perform is exemplified when this participant refers to her success as being due to a teachers' performance or behaviour, rather than any extra effort or progress on her part. Although this is a comment on success rather than failure, implied in this is that this particular teacher was doing something different to other teachers, and therefore deserved credit for H's success:

H.: she just explained things the way that I could understand them—she also used to give us little rhymes to remember things

The informants also apportion blame to other learners.

A.: Ja- in the mixed abilities class there were people that didn't really care and they would just spoil it for everybody else cos they would just interrupt all the time – and disrupt and fidget

It is quite apparent from the data that these children see their scholastic difficulty as a result of the problem with the system and not solely as a result of some inherent weakness or deficit in themselves. This lends support to the view that instead of focusing on fixing the child, giving him/her skills to bring him/her to the point of some mythical average, we should instead be reviewing – possibly revolutionizing – the way we teach our children.

This “externalizing the blame” had a surprising corollary: giving others credit for their achievements:

M.: I made friends quite easily which was quite good because they were the same level – well a little bit higher so they pushed me to work harder----the same level but higher than me intellectually – they were all in my class so that was good...I didn't slack off-it was like influence- they were a good influence on me cos they weren't like –oh I don't care about the test tomorrow –they would be like learning and help me through and help me with things I didn't understand...it was almost like I felt out of place if I did badly – but not like in a bad way – it was like – cos they were getting really good marks and I felt –like not in a bad way – not like I didn't fit in because I didn't do so well– but they were all big on their marks and stuff

One informant's story was different:

S.: but not the teachers – but I think its mainly a problem with me

She continued to see her problem as intrinsic. What is significant, is that S. was the only informant who had stayed in a mainstream environment, albeit

a private school, without being exposed to or experiencing specialised education. This is only a single case, and the nature of this entire study does not allow for generalisability, but I do believe this may add support to my argument that it is the very exposure to a context where all belong to the in-group- the “LD in-group” – that results in a shift to a self –identity that does not include disability.

4. Interpreting their condition:

In the previous section of this chapter I attempted to illustrate how children with LD experience their condition, both in the classroom and in the extra-curricular context. In this second part of the chapter then I will attempt to answer the second critical questions: .How do children with LD interpret their condition? The answer to this will then guide me to the answer to the third critical question: What insights are provided by the life-history approach into the nature of LD and it how can this facilitate pedagogical interventions ? I will deal with the in the final chapter.

The collage overleaf depicts the complexity of LD, particularly how it is experienced.



Figure 7: Collage depicting "how I see my LD" from M.

We see expressions of both positive and negative feelings and experiences: words like havoc, outkast (sic); everyday blues, stress but also positive words like success, smart, surviving, as well as a recognition that the LD experience extends outside of the classroom to sports. From this collage we can see the focus on the academic success/ failure that is marks –driven in our current school system. B. measures his success on his re-admission to mainstream by “better marks” and understands that this is what his time in remedial school was aiming at. M. constantly compares her marks to her peers’ marks, and even when marks are good by objective standards, she is dissatisfied if they are lower than her peers’ marks, according to the standards she sets for herself. This is reference to the structure: the system that is set up and perpetuates itself through both policy and practice.

Success is measured in classrooms by marks, by achieving re-determined goals and learning outcomes. However these goals and learning outcomes are not set by the learners themselves but by policy and curriculum developers.

The interpretation of their condition depicted in the above collage also indicates that it is something which makes them feel like outcasts. This has been discussed in detail in the previous chapter, where I argue that it is not the condition per se that perpetuates this, but the system or structures which exclude them. The issues such as failure, humiliation, alienation all result in “everyday blues” or what I term “exclusion in inclusion.” Miles (1996) stresses the multiple fears experienced by the child he refers to as dyslexic: fear of failure, fear of being different, fear of words, fear of social gaffes. Although in my informants’ stories there is no direct reference to these fears, it is possibly these that result in them experiencing the exclusion in inclusion I refer to.

However there is also a clear indication of acceptance – that the LD is comfortably absorbed as part of who they are but not as what defines them. This is apparent in the following comments from my informants:

M.: now I don't really think of it as a problem at all- it's not that big to me at all

This is possibly as a result of the successes that are recognized. In the previous chapter I discuss both academic success and social success. The academic success is achieved by making choices about what to learn and how to learn:

M.: give you an example of geography – I was absolutely useless- it wasn't cool – but like now you know when I write an essay in history and I'm gonna get it back and I know I'm gonna get a reasonably good mark

A.: I don't think I'll go for art because that's too hard – and I'm definitely not choosing history – and – I won't choose maths – well if I pass maths I'll probably have to go for it but if you fail maths you are not allowed to take it -so – I don't know –I'll have to see- - TD⁶⁷ I enjoy - I really enjoy - and I really enjoy my drama-the work and the practical

H.: and Afrikaans – since I've done Afrikaans its always been harder for me and –I really don't understand –I've tried to learn it but I just don't understand

Both H. and S. dropped the third language requirement and used the additional time to focus on other subjects. H. also made application for a time concession for exams. In this way all have made choices that enable greater success and achievement. The result is that each informant has recognized that they can achieve. The confidence is apparent in the above remark from M., *I know I'm gonna get a reasonably good mark* . It is this that suggests to me that although the LD is a part of who they are, it is not what defines them. One of the primary foci in the reporting of their experiences of LD were the failure and humiliation narratives. Yet as central as these were to at least M., H. and A.'s stories, each one counterbalances the narrative with positive experiences of support, of friendship and even of success. This success is expressed in B.'s family relationships, A.'s sport (rock climbing) and M. and H.'s academic achievements. Even S., who does not overtly refer to failure and does not report the same humiliation related particularly to classroom or academic failure, reaches a point of success reflected in her "I'm OK with who I am" attitude.

The three girls (M., H. and S.) were all in the same grade during the data collection phase, and now, at the time of writing, are all in tertiary education: two studying commerce at university and one studying teaching

⁶⁷ Technical Drawing

at college. This forms a post script to the narratives in that all have achieved a measure of academic success by standards measured currently, in terms of school leaving matriculation exams and acceptances into competitive university and college courses.

How they interpret their condition then for these participants at least, has been in some measure shaped by their success. This is possibly due to a process of self-affirmation (Leary & Tangney, 2003) in particular a process that begins in the remedial school/ unit where they first see themselves facing the same challenges as everyone else in the environment. The reflected self, in other words where they see themselves as they think others see them (Tice & Wallace, 2003) is different in a context where others see them as the *same as* rather than *different from* the majority. I would suggest that here a snowballing effect occurs, when as their own view of themselves changes, this changes the way they think others see them, which, according to the notion of the looking glass self, in turn shapes the way they see themselves. This serves to offset the notion of self that is developed around the time of the early scholastic failure: the mainstream experience of exclusion. As they tend to see themselves as failures at this stage, their view is that others - peers, teachers, and family-see them this way too. What is clear is that their perception of themselves changes in a remedial school/ unit. Once that view of themselves shifted, the strong and positive sense of self perpetuated beyond the “remedial school years” and on into the return to mainstream. Although on return to mainstream they still express bouts of low self esteem, this is not the dominant theme in their narratives. They do present contradictory feelings though:

M.: *Well – now I don't really think of it as a problem at all- it's not that big to me at all – sometimes I think – you know there its shining through and things like that –its never been like a huge thing for me –like you know I'm special and I'm different*

The age at which they were interviewed was no doubt significant too. Each informant was between the ages of 12 and 14 when I interviewed them, in the 'early adolescent' phase development (Gouws et al., 2000). It is during adolescence that we begin to view ourselves from the perspective of others (Ryan & Deci, 2003:254). Our identities change across our life-span and are adapted in the main due to the groups we find ourselves in. There are many factors that impact on the identities we assimilate over time. I posit that for my informants, in fact I would suggest that for children with LD, a temporary identity of disability exists for these children in a mainstream environment, where they are "other," but that this shifts when their (school) context changes. Factors such as family expectations and intrinsic motivation can also impact on the way identities are assimilated (Ryan & Deci, 2003). However I believe my data show evidence of the shift in identity that occurs when the context changes to one where my informants became 'the same as' rather than 'different from' their classmates, and where they had the opportunity to experience success.

All of my informants coped in mainstream or even excelled, and some are at the time of writing this pursuing college or university degrees. This flies in the face of statistics that suggest a high drop out rate (Amen, 2001). All of my informants however had supportive families and in particular parents who were able to provide the encouragement and even in some cases the teaching necessary to support them. All families had the financial resources to fund extra lessons, speech-language therapy, remedial teaching or even placement in remedial facilities. As a result the experiences documented above, especially those related to scholastic failure, were counter- balanced with experiences of success in both academic and social spheres. The academic success is highlighted by M. and H., but even B. mentions he feels "fixed," A. and S. found subjects they enjoy and achieve in. My informants place greater emphasis on social success – all have strong friendships, a supportive circle of friends and M. particularly credits her friends with her academic success, not her teachers. This too contradicts the prevailing view that children with LD have poor social skills and few friends (Kavale & Forness, 1996, Settle & Milich, 1999). At least three of

my informants mentioned friendships that had endured for two or more years at the time of the interviews. All five placed great emphasis on the role of friends in their lives. The support received from friends has been discussed above in section 1.3.2. (Peers and parents).

In the following and final chapter I explore the issue of social success, and the value placed on it by my informants, more fully. It is this that I believe may lead to a shift in focus for educators, and our understanding of the needs of the children with LD. Whilst as educators we place a high value on the academic success, the informants reveal how important social success is. This is typical of adolescents, regardless of whether they have or are “LD” or not (Gouws et al., 2000).

CHAPTER SIX

FINDINGS AND CONCLUSIONS: A SYNTHESIS

1. Introduction

In the previous chapter I presented a detailed discussion and preliminary analysis of my data in an attempt to answer the critical questions posed at the outset. I have shown through this analysis how the learner with LD experiences and interprets his/her condition. In this final chapter I argue for a new understanding of LD, one that moves beyond a perpetuation of the deficit view of LD. I therefore have argued for an alternative understanding of LD, one that would develop from an exploration of the subjective experience of LD. I attempt to tease out emerging patterns in the stories of my informants and propose alternative ways of not only conceptualizing but also managing LD. If LD is understood purely on the basis of definitions, we as educators may only be seeing part of the problem.

It is necessary at this point to revisit the two most commonly acknowledged definitions of LD, those of the DSM-IV and the NJCLD. In the table overleaf I present these definitions as the ostensibly *objective* understanding of LD, or *structure*. I compare this to the subjective experiences of LD, as reported by my informants and discussed in Chapter Five (164). What is core to these two most widely cited definitions of LD, is that LD affects academic performance in specific areas, and that it is thought to be intrinsic to the individual, in other words it has a biological, neurological or physiological basis. Each informant identifies some inherent “flaw” that is the reason for some of their scholastic difficulty, yet whilst they all do acknowledge an intrinsic component to their LD, all place greater emphasis on extrinsic factors, such as environmental conditions.

OBJECTIVE: DEFINITIONS	SUBJECTIVE: EXPERIENCES
<p>DSM IV definition(Thomas, 2000): Learning disorders are diagnosed when the individual’s achievement on individually administered tests in reading, mathematics or written expression is substantially below that expected for age, schooling and level of intelligence.</p> <p>NJCLD definition (Ratner & Harris, 1994): Learning disabilities is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition of listening, speaking, reading, writing, reasoning and mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction.</p> <ul style="list-style-type: none"> • Areas of “deficit” highlighted <ul style="list-style-type: none"> ➤ READING ➤ MATHS ➤ WRITTEN LANGUAGE ➤ LISTENING • Largely INTRINSIC: due to physiological/ neurological or biological malfunction; problem within the child not the system 	<p>The experiences of a child with learning disabilities are of failure, exclusion, humiliation, teasing/ bullying, low self esteem, lack of confidence, even concealment or secrecy. Experiencing acceptance, support, inclusion and friendship is valued as the goal, and viewed as success.</p> <p>The system perpetuates failure by focus on academic success. While the informants mention these academic areas in passing, their focus in their narratives of LD is on the experiences mentioned above, and not the areas of listening, speaking, reading, writing, reasoning and mathematical abilities.</p> <ul style="list-style-type: none"> • Areas mentioned as “deficit” or difficulty <p>Note how in these examples, as the informants describe areas highlighted in the definitions, they minimize:</p> <ul style="list-style-type: none"> ➤ <i>S.: I found <u>a little bit of reading</u> that I couldn’t do as well as the other children– mainly reading and English – not really maths</i> and rationalise : ➤ <i>H.: I take <u>a long time to understand new concepts</u></i> (not: “I can’t,” just “I need time”) ➤ <i>A.: I hate writing... my <u>handwriting’s not good</u></i> • Whilst they acknowledge intrinsic factors to some extent, see it as more EXTRINSIC – blame the system

Table 4: Comparison between objective definition and subjective view of LD

With reference to the extrinsic factors, Sternberg and Grigorenko (2000:6) refer to children with LD as “adopting the mindset of people who are victimized.” I see this in what I refer to as “the blame game” or externalizing the problem, which was discussed in the previous chapter. This is noted particularly in the informants’ narratives after experiencing remedial intervention in special remedial schools or units. What the informants identified as extrinsic causes of their LD has been discussed in the previous chapter. These causes include noisy classrooms, poor teaching such as teachers who cannot control the class, teachers with soft voices, teachers not staying on topic and disruptive peers.

In the following section I identify specific difficulties or components of LD which the informants understand as intrinsic. By this I mean they accept these as part of who they are, part of their self-identity. I refer to this as their understanding of their “deficit.”

2.How they “see” their “ deficits”

H. acknowledges poor spatial perception, word retrieval difficulties and difficulty comprehending certain concepts:

You know there are a few things I really battle with – one of them is- I take a long time to understand new concepts which really bugs me because once I know how to do it – whatever it is –I’m fine with it – but it just takes me such a long time to grasp it – and if I don’t understand it properly then I really battle with it – and then I kind of confuse myself-and another one I battle to understand questions –I don’t understand what they’re trying to say when they do the questions- everyone else seems to know how to answer the questions and how to understand them and I never seem to and I get really annoyed with myself—another thing I really battle with is my reading and how to pronounce- pronounce words –and also remembering words- I could’ve used a word in the sentence before and the next sentence I’ve forgotten it –

I don't understand distances and I can't concept-----the whole concept doesn't come easily to me--I don't ever understand it--even simple little things

B. refers to the intrinsic component as he understands it by conceding that he works “a bit slower” than his peers. He describes himself as “hyper,” with a busy mind, but does not use the ADHD label.

Generally though the tentative nature of their explanations suggests an attempt to minimize or down play the “deficits.” This may be due largely to parents’ attitudes as it was apparent that for all my informants their parents were extremely supportive and made an effort to boost their children’s confidence at every turn. Kathard (2006) found that positive early experiences resulted in people who stutter developing a positive self-identity. I believe the same applies to the children with LD. It further underscores my view that they have each come to a “comfortable co-existence” with their learning difficulties, where they are not defined by them.

M. however is contradictory when she says:

its not a big issue-- like sometimes I think -- you know --well you know there its shining through and things like that --its never been like a huge thing for me -- like you know I'm special and I'm different and [eyes filling with tears despite words being used]

This suggests that clearly there are times when it is still a big issue, there are times when it is like a beacon for all to see. This is also evident in the deep hurt still apparent when she described the spelling and reading errors made in grade 1, ten years previously (SON and PUT discussed in Chapter Four). M. was not the only informant to become emotional in an interview or audio journal entry. However in each case (M., B. and A) the informants became emotional when describing very early school experiences, experiences prior to identification of a disorder, prior to any intervention.

This suggests that in fact the most painful time for them was the time of feeling or being different and not knowing why, the time of feeling isolated and alone.

2.1. How they cope: compensatory techniques

Each informant has developed their own way of coping or compensating for these intrinsic differences. The strategies used include rote learning, pneumonics, review and repetition, and seeking support from peers and parents. B. copes by memorizing, or rote learning. He however believes his time in remedial school “fixed” him in that he does not feel the work in high school is any more difficult for him than it is for his classmates. He describes the role of the remedial school as making him *work better...get good marks and all that*. His growing confidence is evident: *I’m finally getting up to the stage where I can do the work*. H. also uses rote learning and pneumonic strategies taught by a foundation phase teacher. She works long hours and re-learns or reviews consistently, as does A. There is a realisation that they have to compensate, even though they do not discuss it as this. Both S. and H. dropped a subject: the third language requirement. H. was exempt from the third language requirement in primary school and S. in high school. Both therefore used the free time on the timetable to catch up with other work. H. continued to use the time concession as a support, even through her final school leaving exams and in her tertiary education. A. “re-learns” at home. Four out of the five informants use medication to manage the ADHD component.

3. Summary of key findings

The key findings of this research include:

- That the informants with LD experienced “exclusion” in mainstream by virtue of their different performance in the classroom;

- That on removal from mainstream to specialised remedial environments they experienced a sense of belonging, of membership to a group, which allowed them to experience inclusion;
- That the informants' narratives prior to remedial placement revolved around scholastic/ academic failure and the consequences thereof; that there is a shift in focus in the narratives post placement in a specialised education setting to stories of friends and friendship or social success;
- That the informants preferred to go to peers and parents for support by way of additional explanation and re-teaching, rather than to teachers;
- That the use of psychostimulant medication to manage ADHD is not discussed with peers nor, in some cases, teachers; when it is discussed with teachers it is done so reluctantly;
- That the informants began to look outside of themselves for reasons for poor performance as they constructed identities of themselves as “capAble.”

These key findings open up new directions for both intervention or management of these learners, as well as new directions for research.

4. New directions for intervention: Implications for pedagogy

Oliver (1996:10) suggests that: “professional interventions have come to be seen as often adding to [the] problems rather than seeking to deal with them.” Although he is referring specifically to interventions for people with physical disability, I believe the same criticism can be leveled at educators as we seek to support these children with LD. I refer in conclusion to Table 4. Whilst both understandings of LD apply, our current focus in research, remediation and management is on the left column, when the right column also needs addressing. There is a mismatch between what is currently offered to learners with LD based on our “outsider” understanding, and

what these learners suggest they need, based on their “insider” understanding. This is summarized in the table below.

	What we give	What they (say they) want
Policy	Inclusive Education-keep in classroom where there is a constant comparison and highlighting of difference and “otherness” Result: Experience exclusion in inclusion	Separateness- classrooms where there is the comfort of “sameness” Result: experience belonging; in-group membership and thus inclusion
Management focus	academic success: developing literacy Result: Sets them up to perpetuate experience of failure	social success: developing friends and friendships Result: Set up support network that can be used to help achieve academic success
Measure success	Tests, marks, exams: happy teachers Result: focus on deficits	Popularity, sporting achievements: good friends and proud parents Result: focus on achievement; strengths

Table 5: comparison between current focus and expressed need

As can be seen from the table above, the end goal for each of these informants was not academic success primarily; it was to have friends and to make parents proud. Even when goals were related to academic achievement this was rationalized as better marks made parents happy (B.); or to be seen as no different from friends (M.).

What Kathard (2006) refers to as “reframing goals” has significance here. As practitioners it is important to look at the necessity to shift focus from the ‘deficit’ to focus on what the individual needs, or says s/he needs. This may be helping him/her to create or develop a new story and new experiences of success, both in the classroom and outside the classroom; a story where the dominant theme is success, inclusion and sameness rather than failure, exclusion and “Othering.” The shift should allow for a broader focus, not an “either /or.” As LD affects school work, we need even at school to allow for a formal broadening of the support base to include peers and family members. In addition to this we need to recognise achievement across all spheres, as well as a recognition of others who share something in common – a recognition of the sameness as well as an attempt to embrace difference. What is clear from the informants is that this was one of the main issues for them – the experience of being the same as versus the experience of being the Other. The irony is that it is this very philosophy that underpins the inclusive education policy in South Africa (OECD, 2008). Yet it was only when my informants were with others who had similar learning styles, differences or difficulties in the specialized or remedial environment, that they felt this “sameness” and confirmed their sense of being “OK.” Including them in mainstream was what gave them a sense of “Other.” Addressing the low self esteem should be an important part of the management focus (Humphrey, 2002). The experience of specialized educational placement and the resultant experience of belonging to a group, of being ‘the same’ seemed to do this for all my informants to some degree. Frank (2002) and Ingesson (2007) stress the importance of focusing on what the child does well in order to encourage more positive experiences, for example for informant A. this would have been his rock climbing and other sport, for B. it was also his sport, for S. it was her creativity. It is particularly important to highlight their strengths to these children, who are often so lacking in confidence that they feel there is nothing they can do well, or worse that what they do well has no value because of the focus on academic success. I do concede that current education policy does support teaching to develop strengths rather than teaching that focuses on “shortcomings” (OECD, 2008).

In the Venn diagram below I compare what I believe is the educator's *current focus* in the management of learners with LD, as opposed to the *desired focus* of the learners. The size and position of the circles indicates the priority afforded to particular aspects (the larger the circle, the more important that aspect); and the relationship between various aspects.

Note how in the left side of the diagram little attention is paid to social success and the primary focus is on academic success, particularly with regard to developing literacy. This is where educators, including teachers and therapists, invest their efforts and expertise. This is where we attempt to “deal with” or “fix” the deficits of the learner with LD: the deficits outlined in definitions and which are identified by our standardised tests. These include deficits in “reading, mathematics or written expression” (Thomas, 2000:149 quoting from the DSM IV Manual, 1994). Whilst I acknowledge that it is an educator's role to encourage the development of literacy, I am also suggesting that it is imperative that we do not lose sight of what the central focus is for the learners with whom we work. As we invest so much time and emotion in our work with them, it is imperative to look at what they suggest is central to their understanding of success and achievement.

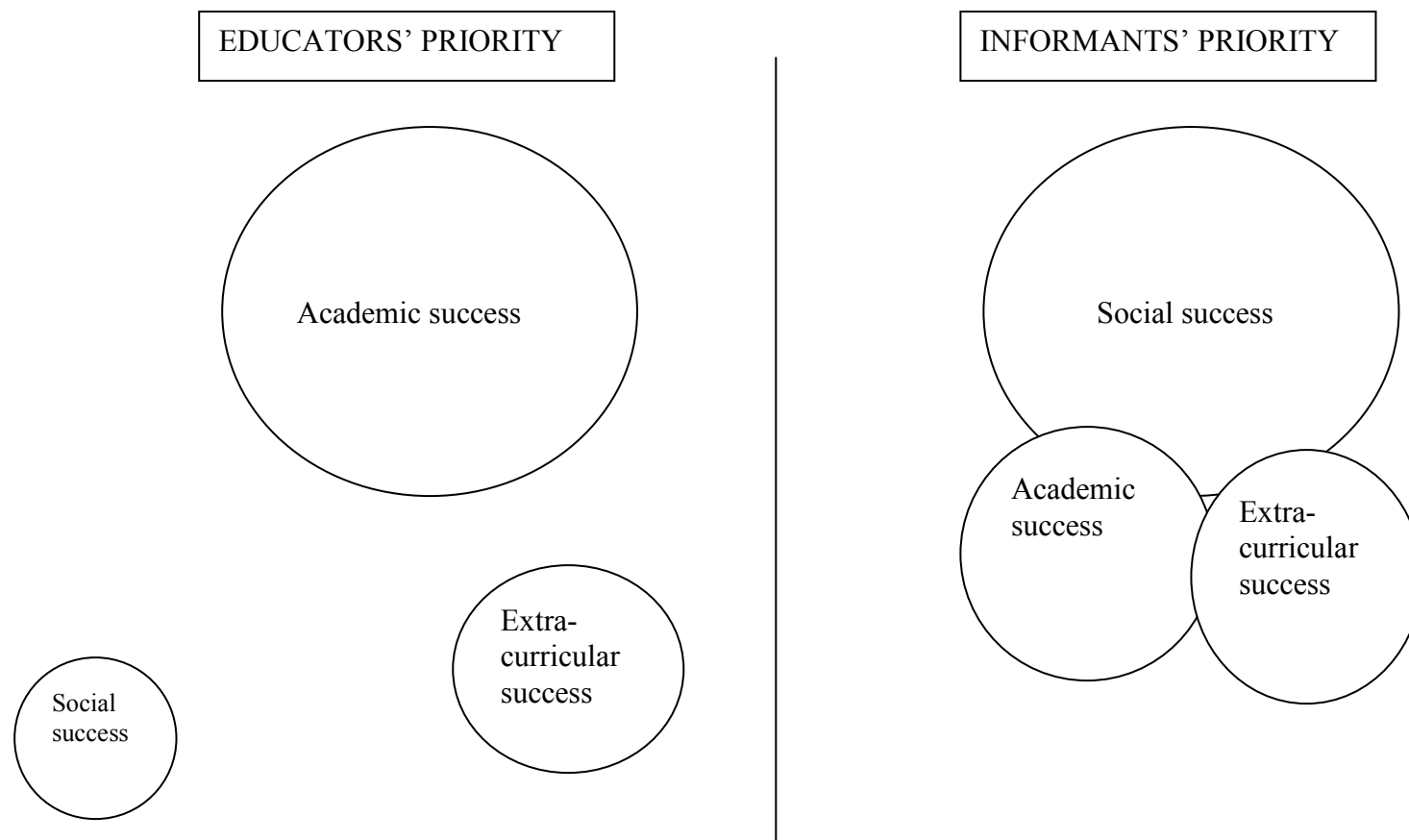


Figure 8: Venn diagram comparing educators' focus with informants' focus

In the diagram on the right we can clearly see the shift that occurs when we reflect on what is central to the learners rather than the educators. While the same issues remain important, the priority accorded to them shifts. Social success, that is popularity, friends and friendships, form the core of the narratives of my informants: that was the area they dwelt on in the telling of their experiences of LD. This suggests to me that it is this social success which tempers and balances the negative experiences associated with the failure they experience daily. In the diagram academic success is linked to social success. This is because it is the friends who provide much of the support necessary for academic tasks: all informants went to friends and family first for extra help if they could not cope with a task or did not understand a concept, before they went to teachers. Those with high achieving friends, such as M., credited their friends with their own academic success, rather than good teachers and teaching. This reflects their own understanding of the important role played by friends, and thus what can be called social success, in leading to their academic success. The implication is that without supportive friends the academic success might not have been possible. It also emphasizes the need for training teachers to cope better with the special needs of these learners.

Regardless of whether one is supportive of inclusive education as a policy or not, the recommendation for a collaborative approach to educational support for learners with special education needs (Engelbrecht, 2001) is laudable. One of the core ethical values for a speech-language pathologist is autonomy, the patient's right to participate in decision-making about his/her treatment.⁶⁸ If we are to consider this, our clients should be involved in decision-making about aims and goals for therapy. We do this readily with adults, but tend to ignore this when working with children. I would suggest that when working with older children and adolescents, this is an important consideration (Gouws et al., 2000). If they are to be part of the decision-making about therapy, this research indicates that priorities for them are not those things which will bring about academic success,

⁶⁸ <http://www.hpcsa.co.za/hpcsa/UserFiles/File/Patient'sRightsCharter.pdf>.

although all strive for this; priority would be addressing those issues which will bring about social success first. For the child with LD, and more particularly with concomitant ADHD, social skills are often inappropriate (Fujiki et al., 2001, Kavale & Forness, 1996, Settle & Milich, 1999). I found with my informants that friends and friendships featured largely in their narratives, not only in the social sense but also as support for academic success i.e. in the classroom. A new focus in therapy could be on developing those social skills necessary to develop and strengthen friends and friendships to the extent that this support can be more fully explored. In this way addressing the needs prioritized by the learners is likely to enhance his/her potential for academic success.

It is also important to address the reluctance of learners to go to educators for support. The fact that the teacher is in fact the last person my informants would go to for support and “teaching” when they did not understand a task or a concept that had been taught suggests that teachers are failing these learners. A. intimates his frustration at this failure when he says he sometimes tells the teacher he understands even when he doesn’t, and then goes home and asks his mother, as *she will explain in a way that I understand*. I believe this comment is an indictment on the teachers and teaching, and a clear indication of a gap in the teacher training curriculum which must be explored and if necessary addressed as a matter of urgency. I am sure it is no coincidence that for each of my informants their recollections of their ‘best’ and ‘favourite’ teachers were the teachers they had in the specialized, remedial environment. I do not believe these teachers were necessarily any better than any other teachers the informants may have had, although some may have had additional specialized training in remedial education. However what was different was the opportunity for success that the teachers engendered in the informants – the teachers made the informants feel good about themselves. Bear et al (1998:92) state:

...some research has shown that children with LD who receive remedial support, regardless of whether such support is in a mainstream or segregated setting, have more positive self-concepts than children with LD who are in

general classrooms in which they receive no remedial support.

It is the positive self-concept, the sense that “I’m OK,” that my informants took with them after their experience in remedial units or schools.

Finally there is scope to explore the palliative, therapeutic and even cathartic nature of narratives and talking about the problem (Rickard, 2004). I found an openness with most of my informants that was almost unsettling at first, and unexpected because of my various roles as an adult, a parent, a therapist, a researcher to them. Yet as the interviewing and journaling process continued, I began to perceive an immense, even cathartic relief in my informants: a relief at having ‘told.’ Even at the outset, when selecting participants, they were eager to tell their stories and be heard. Kathard (2006) details the value of narrative therapy. She argues that narrative – based interventions provide opportunities for shifting the focus of therapy from “fixing the disorder” to exploring of the role of significant other persons in perpetuating or changing the individual’s self-identity. In the case of the child with LD this exploration could include the role of the teacher as well as the actual structures (the school system) in this.

As a ‘trainer’ of future speech-language therapists, the implications for training include reviewing how to use narratives to help in assessment and management for more ‘client –centred’ goals.

5. Future research

Future research should include an exploration of whether “the blame game” is more apparent in learners who have spent time in remedial units or classes and have thus had the experience of belonging to a “group,” than those who have not. With the advent of inclusive education in South Africa, more and more learners with “mild to moderate barriers to learning” are being kept in mainstream classes. Research into how these learners

construct their identities could provide valuable insight into whether inclusive education is in the best interest of the learners.

Another significant direction for future research is a study that looks at the value of early identification and intervention in the form of remedial placement in the junior primary grades, and whether this results in a more confident learner. I suggest that the opportunity to experience a context where one is the same as one's peers, where in a sense the playing fields are leveled, allows for success to be recognized both inside and outside of the classroom. Shared experiences result in a sense of kinship and belonging that is the antithesis of the isolation and marginalization that is reportedly experienced by learners with LD in a mainstream classroom.

A more contentious direction for future research, but a significant one I believe, is research into the financial viability of inclusive education. Current obstacles to including learners with special educational needs in mainstream classes include lack of resources, inappropriate assessment tools and strategies, teachers who are inadequately prepared or trained to deal with the needs of these learners as well as the enormous attitudinal barriers, stigma and, whether we like to admit it or not, discriminatory practices. While the attitudinal barriers do not have financial implications, adequately addressing the former will or should indeed be a costly exercise. Putting a policy into practice requires more than "buy in" from stakeholders; it requires serious commitment to the provision of the necessary resources. Monitoring and evaluating the "roll-out" and provision of the necessary resources may provide useful insight into the level of commitment to this policy.

Research that explores teachers' knowledge, attitudes, perception and management of learners who are different may provide useful information to consider when developing teacher training curricula. Clearly the reason learners seem to go to teachers for help only when all other avenues fail, needs to be addressed.

6. Conclusion:

In conclusion I summarize by answering the critical questions posed at the outset of this study.

Question 1: What are the experiences of learners with LD?

From my informants' stories I can draw the following conclusions. Learners with LD experience exclusion in a system meant to create a sense of inclusion. Donald et al. (1997) suggest advantages to mainstreaming or inclusion include normal peer acceptance, something my findings clearly contradict. For each of my informants the early years of formal schooling was a period fraught with failure, humiliation, frustration and loneliness, resulting in low self esteem. The predominant experience was one of being 'the odd one out' of being different, marginalized, of being "Other."

For each of my informants, early signs of failing to cope in the mainstream system were apparent in the junior primary phase, for some as early as their first year, grade 1. Yet despite this strong friendships were formed, contrary to the literature which states that children with LD have "social skills deficits" and difficulties sustaining friendships (Fujiki et al., 2001, Kavale & Forness, 1996, Settle & Milich, 1999). In fact three of the informants described friendships from that period of schooling that have sustained to the present, in some cases a period of more than 6 years.

All of my informants experienced changing schools within the first three years, even though for ST this was a change due to the family relocating and not to a remedial environment as for the other four informants. However when 4/5 moved to a remedial environment (3 to remedial school and one to a remedial unit), for them in many ways the structure changed, structures such as rules, time-tables, teacher's roles and most importantly expectations, thus their own perception or experience of what was 'normal'. As a result their behaviour changed as they began to experience success, achievement and favourable comparison to peers. They thus begin to shift

the narrative of their lives from one of disappointment, highlighting negative aspects such as failure, to one of contentment, achievement and experiencing success. Their stories reveal a growing sense of their belief in themselves as Able (Kathard, 2006) rather than themselves as less than or in deficit. This sense of self as Able stays with them when they return to mainstream.

All who experienced remedial placement rated these years (2-3) as definitely the best in their schooling, as 8-10 on a 10 point rating scale. Only one was still in a remedial environment at the time of the first interview, while others had been out for 4-5 years; all had been in mainstream for between 1 and 7 years by the end of the data collection process. All had attended at least three schools since grade 1. This finding supports a need for flexibility within the education system to allow for movement between various placement options such as mainstream and specialized schooling (Donald et al., 1997).

Question 2: How do learners with LD interpret their condition?

This can only be answered by referring to their experiences. This question illustrates particularly the tension between structure and agency. In response to this question I illustrate how the learner with LD interprets her condition very differently to the way the labels and diagnostic categories define the condition.

Although each is able to describe facets of LD in themselves, when they justify classroom performance they externalize the blame, in other words they do not use the LD label as an excuse. The LD label implies poor achievement on individually administered tests in reading, mathematics or written expression that is not consistent with expectations given the individual's level of intelligence (Thomas, 2000:149, quoting from the DSM-IV manual, 1994). The focus of educational intervention therefore is on 'closing the gaps.' Yet the way my informants experience their LD depends very much on the environment i.e. experiencing LD in mainstream

versus experiencing LD in remedial education. So how do they define themselves within the confines of the social institutions? In the mainstream classrooms they see themselves stupid, alone, unable to cope, even naughty. However elf –identity in the remedial environment shifts; there is a sense of group membership, which is reinforced by shared practices such as “Ritalin rituals,” where tablets are controlled and dispensed by school staff in a routine manner and children are open about taking the medication. In addition to this they begin to see themselves as smart, able to cope and even able to be competitive academically, and this stays with them on return to mainstream. In fact B. states the he feels “fixed”. They still feel that the teacher is not always able to teach them appropriately and rely heavily on parents and friends for support. What is interesting is that they do not describe this as a story of failure or deficit on their part, but rather as teachers’ lack of skill.

Question 3: What insights are provided by the life-history approach into the nature of LD and how it can be ‘managed’ within the pedagogic context.

Finally there is much we can learn about pedagogical intervention or management from these informants’ experience of LD. If we value what the learners themselves are telling us as educators, we need to look at what their needs are. Their primary need is to be part of a social network- to have a group of good friends who can be relied on to support their learning. There is also evidence to suggest that perhaps specialized educational placement in the short term is not a bad thing. I argue that management should include early transfer to a remedial environment. It is this environment that allows the learners to develop a sense of achievement and of “belonging” to part of a larger group. This is in direct contrast to the mainstream environment in which they experience failure, marginalization and exclusion. The focus in mainstream on academic success perpetuates this, especially as success is measured by performance on tasks/ tests/ exams/ assignments which by any name still reflect a comparison with peers that leaves the child with LD falling short, “in deficit.” However what develops in the remedial environment is a recognition of the

similarities with peers, shared stories (of learning difficulties or differences, of prior failure). Furthermore the focus on addressing the specific needs of each individual child in the that environment allows for strengths to be noted. Strong friendships develop too, possibly due to the shared experiences. My contention then is that remedial placement is important in that it allows these children with LD to develop capacity, experience success, experience a sense of belonging, an awareness that s/he is not alone in this academic struggle. In addition to this the early intervention allows for the experience of success which boosts confidence and self esteem before they experience many years of struggle and failure (Ingesson, 2007). This confidence then stays with them when they return to mainstream, where they are better able to cope not only academically, but also socially and emotionally. In the remedial environment they seem to construct an identity around that which makes them different to the group, which is not their LD. However in the mainstream it is their experience of failure that makes them different, and therefore this is a large part of how they see themselves. This is consistent with the social interactionist notion of the looking glass self (Tice & Wallace, 2003) .

In the first chapter of this report I was critical of the dominant discourse in the field of LD and in particular the fragmenting that has resulted with many disciplines honing in on their specific area of speciality for research. Somewhere in all of this we have lost sight of the child – the “sufferer” of LD. I suggested that if we looked at this condition from the child’s perspective we may gain a different, perhaps wider, understanding of it. I do not attempt to offer an alternative definition here. I do not believe there should be an “either/or” competition. However I hope that what I have shown is that the way the child with LD interprets his/her condition is dictated to a large extent by context. The question we then should be asking is: if identity is constructed differently in different contexts, what does this say about the way we define learning disability? The irony is that it is only when s/he is excluded from the mainstream that s/he begins to lose sight of her condition as a weakness, and see him/herself as ‘normal.’ It is in the mainstream, in an environment where s/he is faced with failure,

humiliation, teasing, disappointment and unfavourable comparison, where his/her difference is most noted, that his/her LD is understood as a deficit. It is only in the mainstream that the “identity as LD” is constructed because of the comparison to the performance of peers where s/he stands out as different. However in a specialised educational environment where peers all presented with the same learning differences, difficulties and styles, instead of comparison there is a sameness. This I believe leads to the development of an “identity as capAble.”

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APPENDIX I

1. BAUMINGER, N. & KIMHI-KIND, I. (2008) Social information processing, security of attachment, and emotion regulation in children with learning disabilities. *Journal of Learning Disabilities*, 41, (4):315 - 332. (fragments: 3 components)
2. CHIAPPE, P. (2005) How reading research can inform mathematics difficulties: the search for the core deficit. *Journal of Learning Disabilities*, 38, 313 - 317. (deficit focus)
3. LOPEZ ESCRIBANO, C. (2007) Evaluation of the Double-deficit hypothesis subtype classification of readers in Spanish. *Journal of Learning Disabilities*, 40, 319 - 330. (deficit focus)
4. SAVAGE, R., FREDERICKSON, N., GOODWIN, R., PATNI, U., SMITH, N. & TUERSLEY, L. (2005) Relationships among rapid digit naming, phonological processing, motor automaticity, and speech perception in poor, average, and good readers and spellers. *Journal of Learning Disabilities*, 38, 12 - 28. (fragments: 4 components)
5. SAVAGE, R. & FREDERICKSON, N. (2006) Beyond phonology: what else is needed to describe the problems of below-average readers and spellers? *Journal of Learning Disabilities*, 39, 399 - 413. (deficit focus)
6. SCHUCHARDT, K., MAEHLER, C. & HASSELHORN, M. (2008) Working memory deficits in children with specific learning disorders. *Journal of Learning Disabilities*, 41, 514- 523. (deficit focus) (fragmentary)
7. VAN DER LEIJ, A. & MORFIDI, E. (2006) Core deficits and variable differences in Dutch poor readers learning English. *Journal of Learning Disabilities*, 74 - 90. (deficit focus)

APPENDIX 11

Interview schedule: probes to guide conversation

INTERVIEW PHASE ONE (which may include more than one interview):

Purpose: To begin generating a comprehensive “general life story”

Step 1: read and discuss short biographies from literature, discuss the idea of telling one’s “life story”

Step 2: Using art material (pictures, photographs; school books or reports) allow child to represent important events in his/ her life.

Step 3: Use these artifacts to start talking about his/ her life.

Conclude: Continue general discussion, building rapport and establishing trust between researcher and child. Prime the child that future interviews will look at life chronologically. Encourage him/ her to bring photographs/ other artifacts that may stimulate recall.

INTERVIEW PHASE TWO (which may include 2-3 interviews)

Purpose: To discuss experiences at school

NOTE: As there may be more to discuss and more recall of more recent school history the interviews may cover more than one school phase, particularly interview 3 where both preschool and primary school may be discussed. In other words there will be no strict cut-off point for each interview and again more than three interviews may be necessary, particularly with older informants

Opening: Let’s talk about your life at school. Tell me about:

- Preschool
- Primary school
- This school

Specific questions may be as follows:

What’s your favourite thing to do at school?

What do you like most about school?

Or⁶⁹: Which subject do you enjoy most? Why?

Who is your favourite teacher? Why?

What do you find most helpful at school?

Is there anything you don’t like about school? Tell me about it.

Or: Which subject do you enjoy least? Why?

Are there any things at school you really dread having to do? Tell me about them.

⁶⁹ The alternative questions may be asked to older informants

What sort of work do you find difficult? Why?

How do you deal with work you find hard?

How would you describe your school life?

What is your best memory of school?

What is your worst memory of school?

INTERVIEW PHASE THREE:

Purpose: To discuss experiences away from school, with particular focus on at least one extra-curricular activity where the child experiences success

Opening: Let's talk about your life away from school

Specific questions may be as follows

Tell me about your extra-curricular activities

What do you like best? Why?

How do you spend your time at home

What do you do for fun/ pleasure?

INTERVIEW PHASE FOUR:

Purpose: To explore how the child experiences his/her LD

Let's talk about your LD⁷⁰

Specific questions may be as follows

Why are you in this class / school?

How do you feel about the difficulties you have?

Do you think your parents understand your learning difficulties?

Do you think your brothers/ sisters understand your learning difficulties?

Do you think your friends understand your learning difficulties?

⁷⁰ As informants will either currently be in a remedial unit or have returned to mainstream after a period in a remedial unit, this direct reference to and labeling of their LD is something that has already occurred.

Do you think your teachers understand your learning difficulties?

Do you talk to your parents about your LD?

Do you talk to your friends about your LD?

What does it mean to you to have LD?

How would you like to be treated- by teachers?

How would you like to be treated- by family?

How would you like to be treated- by friends?

Have you had any embarrassing experiences because of your LD?

INTERVIEW PHASE FIVE:

Concluding interview/s, further exploration of issues raised in previous interviews where necessary

Specific questions may be as follows

Is there anything you'd like to talk about .../ anything you wanted e to ask about that I did not ask?

(Probes may also guide conversation back to issues raised in previous interviews that may warrant further exploration.)

APPENDIX III

Data Analysis Schedule/ Matrix

MATRIX: EXPERIENCES OF SCHOOL AND CURRICULUM

	transcript	Pg no:
TEACHERS		
WORK (CLASS; HOME)		
SPORT		
FRIENDS		
Other/ additional		

MATRIX: EXPERIENCE UNIQUE TO CONDITION/ DIAGNOSIS

	T/SCRIPT	PAGE
MEDICATION		
SCHOOL PLACEMENT		
ADDITIONAL SUPPORT (RT; OT; SLT)		

MATRIX: FEELINGS/ EMOTIONS

POSITIVE	PAGE	NEGATIVE	PAGE
EXCITEMENT		ISOLATION/ ALIENTAITON/ MARGINALISATION	
HAPPINESS/ JOY		HUMILIATION/ EMBARRASSMENT	
ACHIEVEMENT		FAILURE/ REJECTION	
SELF-WORTH/ SELF ESTEEM		GUILT	
COMFORT/ FAMILIARITY		SADNESS	
		FEAR – OF FAILURE OR WORDS OF... OF..	

APPENDIX IV

Letter: Ethical clearance

APPENDIX V

Letter to parents: Introductory

Letter: Informed consent for parent and informant

PENNY FLACK

SPEECH AND HEARING THERAPIST

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Dear Parents,

I am a doctoral student currently conducting research into the experiences of children with learning disability, with a focus on what they say rather than what their teachers, therapists or parents say. Your child _____ has been identified as a possible participant in this research project. Obviously before embarking on ANY research I will seek your full consent and that of your child. To this end I would like to meet with you to discuss the full aims and implications and answer any concerns you may have about the process or its outcomes.

I am prepared to meet at a time and place that suits you, and would therefore appreciate it if you could indicate your preference below. As it is school holidays, could you please either fax this back to me at 2044622 or e-mail me at either of the above addresses. I look forward to your response.

Penny Flack

(P.S. I have included a brief "pen sketch" overleaf, for your information)

PLEASE INDICATE YOUR PREFERENCE

- ☐ I AM interested in allowing my child to participate in this research
- ☐ I AM NOT interested in allowing my child to participate in this research
- ☐ I would prefer to discuss this further before responding
- ☐ I would prefer to meet at my home one morning or afternoon
- ☐ I would prefer to meet at my home one evening
- ☐ I would prefer to meet at SCHOOL one morning
- ☐ I would prefer to meet at SCHOOL one afternoon

SIGN _____ PARENT
OF _____

PENSKETCH: PENNY FLACK

I am a registered doctoral student in the Department of Educational Studies at the University of Durban-Westville. I currently lecture in the Speech and Hearing Therapy department at the same institution where one of my tasks is the supervision of the students in the language learning disabilities clinic.

I have a special interest in children with learning disability. I was a speech therapist at Livingstone Remedial School for 10 years (1991-2001). On a more personal level I am a parent of a child who spent two years in a remedial unit.

In 1997 I was awarded a Master's degree in Linguistics (Stellenbosch) and the focus of my research was on linguistic politeness in children with ADHD.

Although much research has been conducted in this field, each discipline approaches the problem differently and focuses on the specifics. I believe research does little to show us that these children are more than "classroom problems," poor writers or spellers, poor readers etc,. I believe by focusing on the specifics we are missing the "big picture." It is also imperative, I believe, to see this issue from the child's perspective – what he/ she says is or is not important about his experiences- if we are to plan appropriate intervention. So the questions I aim to answer through my research are, broadly:

1. How do children with learning disability experience their disability in the school environment?
2. How do children with learning disability experience their disability in their extra-curricular activities?
3. How can we use knowledge of these experiences in management of learning disability?

PENNY FLACK

SPEECH AND HEARING THERAPIST

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Dear

I would like to use _____ as a participant in my research. I have spoken to him at school and advised him that both your consent and his consent will be sought for this and that he is under no obligation to accept this request. However if, after discussion you and your son are still happy to be involved, would you please sign the consent form below and return to school on Monday if possible. The participants will then receive the equipment and materials they need to begin recording the audio journals, the first part of the process. The video room will be set up at school by the new term.

Thank you for your support

CONSENT FORM

I hereby give my consent for my son/ daughter _____ to be a research participant in the project described to me and titled "Citrus clouds on planet Goofy: the lived experiences of children with learning disability." I understand that anonymity and confidentiality is ensured at all times and the research procedures and processes will not be changed without my further consent.

SIGNED BY LEGAL GUARDIAN: _____:

WITNESS: _____

Signed at _____ this ____ day of _____ 2003

I hereby agree to be a participant in the research project described to me by Penny Flack about the lived experiences of children with learning disability. I understand that my name and identity will be protected at all times and I may leave the project at any time.

SIGNED BY PARTICIPANT _____

WITNESS: _____

Signed at _____ this ____ day of _____ 2003